Successful community living: a 'UTOPIA'?

A survey of people with severe mental illness in
Dutch Regional Institutes for Residential Care

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Successful community living: a 'UTOPIA'?

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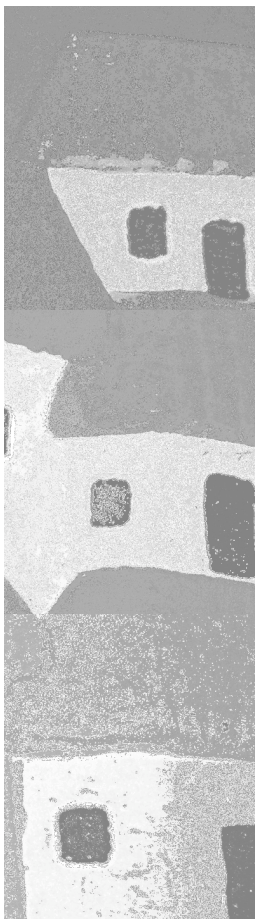

Introduction

This introductory chapter focuses on the transition in mental health care provision from the asylum to the mental hospital to community care, with an emphasis on housing programmes. The Dutch deinstitutionalization process, and especially the development of Regional Institutes for Residential Care (RIRCs), is discussed in detail. Finally, the UTOPIA study into Dutch RIRCs and their service users and an outline of this thesis are described.

Early developments in psychiatric care

Where it all began: the asylum

The first asylums for people with severe mental illness (SMI), who were at that time depicted as the insane, idiots and lunatics, were developed as early as 1403 in London, England. These asylums were created to protect society from the mad. They often resembled prisons, and admission to and discharge from these facilities was mostly involuntary and a judicial matter. The conditions for the incarcerated were harsh. In the late eighteenth century efforts were made for their improvement, e.g. by prohibiting the use of chains, providing therapy based on work and exercise, and promoting moral behaviour. However, overall these efforts had limited effects on the quality of life of patients (Goodwin, 1997). In the nineteenth century and the first half of the twentieth, the number of asylums across Europe increased. For example, in Spain there were no asylums in 1860 but in 1975 the total number of asylums had grown to 116 (Comelles & Hernáez, 1994). In Ireland, where the first asylum was built in 1810, a total of some 20,000 people were incarcerated by 1958 (Walsh, 1987). Although legislation to build asylums and to define the conditions for admission (use of coercion, length of stay etc.) was introduced (e.g. the Lunacy Act of 1821 in Ireland and the Dutch Krankzinnigenwet of 1884), circumstances did not improve (Goodwin, 1997).

From 'asylum for idiots' to 'hospital for the mentally ill'

In the first half of the twentieth century preliminary attempts began to transform the asylum into a hospital-like facility. For example, in the Netherlands the so-called 'bed and bath treatment' was introduced to treat the symptoms of agitated and nervous patients (Blok & Vijselaar, 1998). Psychiatrists started to experiment with open door policies, industrial therapy was developed and new physical treatments were introduced, such as the malaria cure for the treatment of dementia paralytica, the insulin coma cure for schizophrenia, and electroshock therapy for major depression

(Blok & Vijselaar, 1998). The asylums gradually made the transition from custodial institution to treatment facility. With this transition, the terminology used in mental health care legislation changed. Insane or lunatic became 'mentally ill'; the 'lunatic asylum' was referred to as the 'mental hospital' (Goodwin, 1997). From the latter part of the nineteenth century onwards, small-scale efforts were also made to develop alternative care. This emphasis on care outside the asylum continued to grow in the next century. Around 1930 extramural services started to emerge in several European countries. The Second World War had a substantial effect on mental health care provision. Shortage of food meant that in many places inpatients risked starvation, and many people with SMI were placed in the community for the sake of their own survival (Demay, 1987). However, this did not prevent the mental hospital continuing to grow after the Second World War. In the 1950s, the largest European mental hospitals had from 1200 to 4000 beds (Goodwin, 1997). At that time, it became apparent that these institutions did not provide an appropriate environment to recover from mental illness. The hospitals were too large, too isolated from the community, and too neglected to be therapeutic (Goodwin, 1997). New legislation on the provision of mental health care became more and more focused on the rights of these patients to live a life like any other citizen. For example, in England the Mental Treatment Act 1930 and the Mental Health Acts 1959 and 1983 promoted outpatient care, allowed for voluntary admission and enabled patients to appeal against involuntary admission (Turner, Deahl & Salter, 1999).

Deinstitutionalization: from the long-stay psychiatric hospital ward to housing programmes in the community

From the 1950s there was a growing awareness that people with SMI should be supported in their own environment, with more emphasis on prevention and rehabilitation and with the aim of improving their social integration. The medical model was no longer central (Novella, 2010). Mental hospitals across Western Europe were closed or reduced in size accordingly. This deinstitutionalization process varied across countries, depending on geographical characteristics, the national culture, the political and economic system, the organization of the mental health care system itself etc. (Becker & Vaszquez-Barquero, 2001). For example, in Italy all psychiatric hospitals were gradually closed over a period of 20 years – starting in the 1970s with Reform Law 180 – through the cessation of new admissions (Piccinelli, Politi & Barale, 2002). In the UK, the Hospital Plan for England and Wales (1962) aimed at the closure of half of all mental hospital beds by 1975. In 2001, of the original 130 psychiatric hospitals only 14 still existed, with less than 200 service users each (Leff, 2001).

In the Netherlands, deinstitutionalization followed a different course. Charitable and religious groups mainly founded and ran the Dutch asylums. In the 1920s the Netherlands was one of the first European countries to develop community-based mental health services through clinics in the community (Goodwin, 1997). A social psychiatric service system emerged apart from the asylum. For example, the prominent doctor Arie Querido advanced this development by establishing a community-based mental health service in Amsterdam in 1934 (the Querido Foundation, one of the predecessors of the RIRC HVO Querido) (Goodwin, 1997). This service aimed to organize prevention and after care more efficiently and to reduce the costs for the local authorities. Still, these developments did not lead to a large-scale shift of mental health care from residential to the community. Health insurance companies were reluctant to provide funds for services that were not primarily focused on treatment. Also, the contributions of the authorities were insufficient to enhance community services (Giel, 1987).

It was only in 1971 that the Hospital Act and other government Memoranda initiated a policy that promoted smaller, regional psychiatric services and discouraged the use of the old and large mental hospitals (Haveman, 2001). In 1972 the Dutch Association for Community Mental Health Care was established. In a Memorandum in 1974 it stated the aim of creating Regional Institutes for Ambulatory Mental Health Care (Dutch acronym RIAGGs). These RIAGGs should prevent hospitalization and provide care to everyone in need. At the same time, mental hospitals improved their care. They started to increase their outpatient and day-patient care and renovated their inpatient facilities (Schene & Faber, 2001).

In 1983, the Chief Medical Inspectorate for Mental Health Care issued a report advocating flexible, regional housing facilities. These so called Regional Institutes for Residential Care (RIRCs; Dutch acronym RIBW) should provide housing to former patients of mental hospitals and were seen as a separate sector between the mental hospital and the RIAGGs. In the so-called New Memorandum (1984, Dutch: de Nieuwe Nota) their position and function as residential care facilities within the mental health care sector was elaborated further. The government prescribed the regional boundaries within which these RIRCs should operate. Existing housing programmes, originating from the 1950s and 1960s and founded by non-statutory agencies, were forced to merge into their regional RIRCs. This strategy led to conflicts between mental hospitals and these agencies over who should care for these service users (Giel, 1987; Goeman & Van Zuthem, 2007). The relationship between RIRCs and

mental hospitals would continue to be somewhat strained (Goeman & Van Zuthem, 2007).

Dutch deinstitutionalization did now gradually take shape. However, the economic recession in the 1980s and the ability of mental hospitals to oppose the substitution of RIRC provision for hospital beds and to develop and increase their own outpatient care, slowed down the development of community housing programmes as a mental health sector (Goeman & Van Zuthem, 2007). A stable number of around 3000 people with SMI resided in RIRCs during the 1980s. In the next decade RIRCs progressed through the rearrangement of funds for care innovation, which enabled them to invest in new initiatives in the area of supported housing and also daytime activities. Their residential beds increased to about 5000 between 1989 and 1999 and outpatient care was made possible for about 3500 people with SMI who lived on their own (Goeman & Van Zuthem, 2007). In 1988 there were 59 RIRCs in total (Van der Veen, 1988) of which 21 remain.

In the late twentieth and early twenty-first century two separate processes can be identified in Dutch mental health care. Next to deinstitutionalization, there is a trend of integration of mental health care services (Van Oostveen & Hummelen, 2001). This second movement results from the introduction of the Care Insurance Act (Zorgverzekeringswet) and the Social Support Act (Dutch acronym: WMO), which have unfavourable financial consequences for relatively small care organizations, due to higher demands on quality, flexibility and competition (Goeman & Van Zuthem, 2007). As a result, many RIRCs have merged with local mental hospitals and RIAGGs to become large regional mental health care institutions.

RIRCs in the twenty-first century

Institutional developments

At the time of writing there are 21 RIRCs all of which collaborate in the RIRC Alliance. The latter is an association to protect the position of RIRCs in the mental health care sector, and to influence national policy concerning the support and social position of their service users. RIRCs provide three types of community services. First, supported housing that is allocated when a person with a severe psychiatric impairment needs a protective living environment and/or permanent supervision. Generally, supported housing facilities are one-family homes in a regular neighbourhood that provides

accommodation for three or four residents. Each has their own bedroom, but they share the bathroom, kitchen and living room. General house rules are set up by the RIRC and residents can also make specific mutual agreements. Key workers and other support workers supervise the household. Second, RIRCs support independent living for people with SMI who have moderate or severe impairments in the area of social independence, mental functioning, cognitive skills or moderate to severe behavioural problems, without the need for permanent supervision. Key workers, who provide psychosocial and practical support, visit these people in their own home. Finally, RIRCS have boarding houses for homeless people with psychosocial problems. However, this care provision is beyond the scope of this thesis, in which we focus on supported housing and supported independent living.

From the late twentieth century to today, RIRCs have developed into a distinctive mental health sector. In 2006, RIRCs provided supported housing to 5548 people. This is a mean of 6 per 10,000 of the total population of their catchment areas and also roughly half of the total number of beds in sheltered accommodation, including those of the mental hospitals (Van Hoof, Knispel, Van Wijngaarden et al, 2009). Additionally, the RIRCs provided supported independent living to 6797 people, a mean of 7 per 10,000. This is also roughly half the number of people who need this kind of support (Dutch Mental Health Care Report, 2009). Between 2006 and 2009, the expansion of RIRCs continued with an exponential increase of 45% in supported housing (to 8061 residential beds in 2009) and an increase of 46% in supported independent living programmes (to 9943 independently living service users). This remarkable increase in the number of RIRC service users is not accompanied by a decrease in mental hospital beds, which implies that there are more beds available for people with SMI during this on-going deinstitutionalization process than before. This phenomenon is also defined as 're-institutionalization', which denotes the process of creating 'community institutions' in the form of housing programmes, and also entails an increase in the number forensic beds and people with SMI who are imprisoned for criminal offences, and the rise of involuntary admissions. The same process is taking place in other Western European countries as well (Becker & Vazquez-Barquero, 2001).

Critics have stated that community integration might have succeeded in theory, but not in practice. At present, many people with SMI live in a regular neighbourhood, in an ordinary house, but real social inclusion is still far away. They have limited or no contact with their 'normal' neighbours, do not have a paid job, do not participate in sports or social activities with others than their housemates or peers etc. In this view,

these community-housing programmes seem to resemble golden cages, instead of offering golden opportunities for social inclusion. Nevertheless, despite the enormous expansion of housing capacity all RIRCs have waiting lists varying from six months to over a year. In January 2006, at least 1214 people were waiting for allocation to supported housing. This number had grown to 1507 in 2009. At least 473 people were waiting for support in their own home in 2006, and this waiting list had grown to 663 people in 2009 (De Heer-Wunderink, Caro-Nienhuis, Sytema et al, 2007). Table 1 provides a short overview of the socio-demographic and clinical characteristics of both service user groups.

Table 1 Socio-demographic and clinical characteristics of service users of RIRCs in 2006*

	Supported housing		**Supported independent living**	
Age (n=8013), mean (sd)	46	(15.3)	45	(13.9)
Gender (n=8013), male, % (n)	63	(2386)	55	(2324)
Civil status (n=6594), % (n)				
• Unmarried	81	(2581)	75	(2555)
• Married	2	(64)	7	(239)
• Divorced	14	(446)	14	(477)
• Widowed	3	(96)	4	(136)
Diagnosis (n=4809), % (n)				
• Schizophrenia	57	(1364)	42	(973)
• Anxiety/depression	17	(415)	31	(712)
• Other	26	(609)	28	(640)
Substance use disorder (n=5514), % (n)	24	(653)	19	(530)
Personality disorder (n=5348), % (n)	29	(763)	34	(923)
Years in RIRC care (n=5600), mean (sd)	6	(6.0)	4	(3.5)
Living situation before RIRC (n=3567), % (n)				
• Independent	21	(356)	64	(1199)
• Family home	9	(153)	7	(131)
• Mental hospital facility	54	(915)	2	(393)
• Other RIRC	8	(135)	3	(56)
• Other	8	(135)	5	(94)

* Due to incomplete administrative registration of service user characteristics by RIRCs, the number of service users differs between variables. For each variable, the total number of available data is mentioned in the table

Around half of the residents come from a mental hospital, but as many as 30 to 40% originated from the community either from an independent living situation, a family home or another living arrangement (Table 1). In the light of re-institutionalization, one could question if these people are currently better off.

Care allocation

According to Table 1, service users in supported housing and supported independent living programmes are quite similar. In 2009 we conducted a second administrative data round and found this to be unaltered (Caro-Nienhuis, De Heer-Wunderink, Sytema et al, 2010). On average, service users are middle aged, more than half are males, and around half are diagnosed with schizophrenia. A quarter or fewer have a substance use disorder and about a third a personality disorder. People in supported housing do show a longer duration of stay and are also more likely to have come from a mental hospital facility (e.g. a long-stay ward, or community housing programme). The similarity of these service-user groups has recently become an important issue for future RIRC policy. Pressured by recent cuts in mental health care funding and the extramuralisation policy of mental hospitals, the question arises whether a part of the RIRCs' current residential population is able to make the transfer from the more institutionalized supported housing programmes to supported independent living programmes. This measure should have bilateral results. First, it should create room in residential facilities for former mental hospital patients and, second, it should entail a cut in costs. Because supported independent living has lower care intensity and is conducted in the service user's own home it should be more economical than supported housing. Additionally, such a transfer could also have positive consequences for the residents involved, in terms of enhancing their social inclusion. Given the ideological principles on which RIRC care is based, which presume service users' psychiatric rehabilitation and social inclusion, RIRCs should be up to this challenge.

Rehabilitation and recovery: the road to social inclusion

RIRCs are independent mental health care organizations that are distinguished from hospital-based facilities by their focus of care. Central to their care provision is the Psychiatric Rehabilitation approach (Anthony, Cohen & Farkas et al, 2002)) developed by the Centre of Psychiatric Rehabilitation at Boston University, Massachusetts. Instead of primarily treating the service users' psychiatric impairments, this approach revolves around finding and tapping their strengths and possibilities. It is aimed at enhancing the service users' self-help skills and promoting their social inclusion. Key

workers are trained in applying rehabilitation principles in their support. The outline of the standardized treatment plans is shaped accordingly. Essential to psychiatric rehabilitation is the equality of service users and key workers in the therapeutic relationship. Key workers help service users to determine their own priorities. Rehabilitation goals are formulated according to the service user's wishes. Shared decision making, in which the service user and key workers make mutual decisions on the direction of support, is an important part of RIRC care. RIRCs promote their institutes as being bridge-builders between mental health care services on the one hand and society on the other (Goeman & Van Zuthem, 2007). In this capacity, they provide day centres, sheltered employment projects and job coaching to facilitate the transfer of their service users to vocational participation (De Heer-Wunderink, et al, 2007).

The UTOPIA study

There is great variety between countries in the degree to which research has been able to explore and monitor deinstitutionalization in mental health services. In the UK and Italy, countries where most if not all psychiatric hospitals have been closed rather than downsized, research has succeeded in keeping up with these changes. The TAPS study in the UK (Knapp, Beecham, Anderson et al, 1990; Bigelow, 1998; Leff & Trieman, 2000) and the PROGRESS study in Italy (De Girolamo & Cozza, 2000; De Girolamo, Picardi, Santone et al, 2005; Gigantesco, Picardi, De Girolamo et al, 2007) have documented the consequences for service users and providers most extensively. In the Netherlands, only a limited number of studies into deinstitutionalization were published before 2006. Schene and Faber (2001) describe the reform of mental health care in the Netherlands from 1970 to 2001. Other studies are mainly based on psychiatric case register data (Pijl & Sytema, 2004; Pijl, Sytema, Barels et al, 2002), or focus on partial hospitalization (Schene, Van Lieshout & Mastboom, 1986; Schene, Van Wijngaarden, Poelijoe et al, 1993; Kluiter, Giel, Nienhuis et al, 1992). These studies indicate that there are no therapeutic, social or economic impediments to actively promote and enhance deinstitutionalization. Apparently, the mental health institutions were able to slow down this development due to inadequate governmental regulations. There are also various studies and reports published in Dutch. For example, a study on staff views on the relocation of service users from the hospital to the community (Borgesius & Brunenberg, 1999), a study describing service users' daily lives in long-stay facilities (Van Wijngaarden, Bransen & Wennink, 2001),

descriptions of local substitution projects (Wiersma, Brook, Giel et al, 1991; Ruphan, Kluiter, Nienhuis et al, 1992), a report on the RIRC sector of the Dutch Mental Health Association (RIBW in cijfers, 2000), a study into the ethical aspects of deinstitutionalization (Bauduin, 2001), and a report on quality of care in the RIRC of Utrecht (SBWU; Van Wijngaarden, Wennink & Kok, 2005). However, general knowledge based on thorough large-scale research into community housing programmes and their consumers is lacking.

The Dutch UTOPIA study (UTilization and Outcomes of Patients In the Alliance of Dutch RIRCs) funded by the RIRC Alliance between 2006 and 2012 is aimed at providing this information. The two main service user groups in community housing programmes are studied in terms of their socio-demographic, clinical and care characteristics. Additionally, information is gathered on qualitative aspects of community living for people with SMI, such as their level of functioning, needs for care, quality of life and satisfaction with care. This information is aimed at supporting and enhancing future policy and care practice e.g., in relation to care allocation and social inclusion.

The UTOPIA study is the first large-scale cross-sectional survey on Dutch psychiatric community housing programmes and is conducted in two phases. The first phase consisted of an inventory of RIRC care and service users. All RIRCs provided administrative data on their care provision (e.g., bed capacity, care production, staff information, and additional care provision, such as day centres and sheltered employment) and on the socio-demographic and clinical characteristics of all service users. The results are described in a Dutch report, which presents an overview of the status quo in community housing programmes (De Heer-Wunderink et al, 2007). The second phase consisted of a survey of service users and their key workers. The flowchart in Figure 1 on the next page provides an overview of participating RIRCs, key workers and service users. Service users' level of functioning, needs for care, quality of life, satisfaction with care, time use and helping alliance between key workers and service users, were investigated in greater detail and in relation to other European countries. Care allocation and social inclusion are areas of special interest. This thesis is based on data from this second phase. The general results are also published in Dutch (De Heer-Wunderink, Caro-Nienhuis, Sytema et al, 2009).

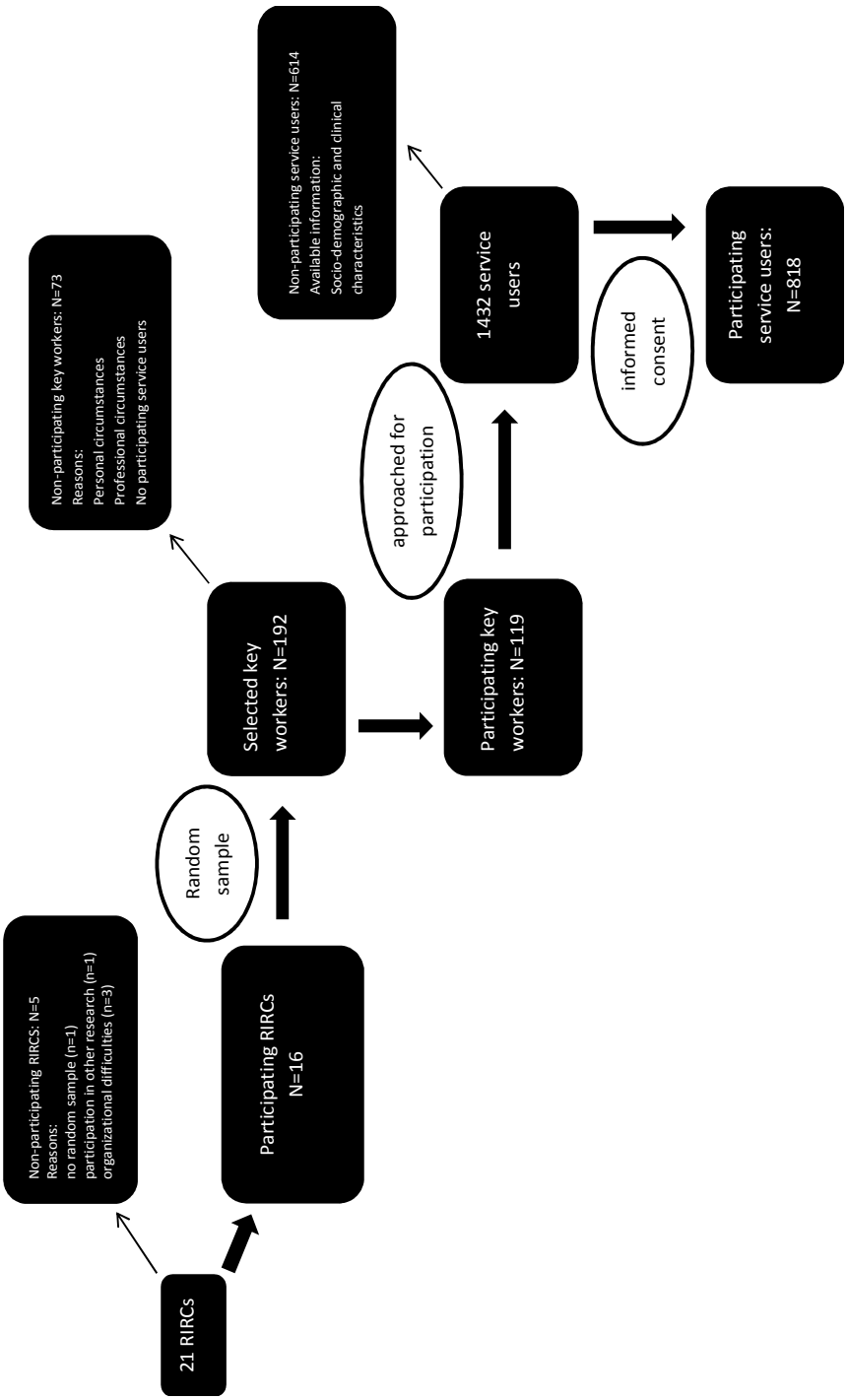

Figure 1 Flow chart of participation in the second phase of the UTOPIA study

Outline of this thesis

In chapter 2, residents of supported housing programmes in the Netherlands are compared with their Italian counterparts. The question is raised whether the differences in the mental health reform and deinstitutionalization between the two countries have led to different service user populations. Data from the first phase of the UTOPIA study are used.

In chapter 3, the allocation of people with SMI to supported housing programmes and supported independent living programmes in the Netherlands is investigated. We compare service users between programmes, to find out if service user characteristics are associated with their care allocation. Additionally, we compare the Dutch programmes and their service users with similar programmes and service users in the UK.

Chapter 4 describes the social inclusion of Dutch residents and independently living service users on the basis of service user diaries. Social inclusion is operationalized as 'activities', 'visits' and 'vocational participation'. Additionally, we examine the relationship between type of housing programme and social inclusion.

Chapter 5 presents a new method to screen the written treatment plans of RIRCs for their adherence to rehabilitation principles. We have screened 255 treatment plans accordingly. Additionally, the degree of adherence to rehabilitation principles is associated with unmet needs for care. We hypothesize that a better adherence to rehabilitation principles is associated with a higher correspondence between treatment plans and unmet needs.

In chapter 6 the helping alliance is investigated and its interrelationship with levels of functioning and (agreement on) need for care of service users and key workers in supported housing and supported independent living programmes.

The main findings of this thesis are discussed in chapter 7.

An English and a Dutch summary are provided at the end of this thesis.

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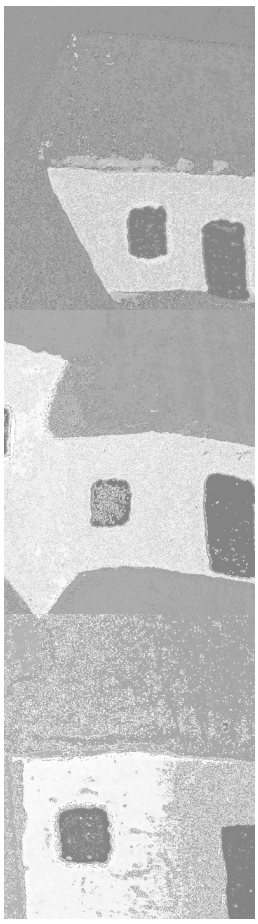

Residential care: Dutch and Italian residents of residential care facilities compared

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Charlotte de Heer-Wunderink, Annemarie-Caro-Nienhuis, Sjoerd Sytema, Durk Wiersma

Epidemiologia e Psichiatria Sociale, 17, 2, 2008

Abstract

Aims

Characteristics of patients living in residential care facilities and the availability of mental hospital- and residential beds in Italy and The Netherlands were compared to assess whether differences in the process of deinstitutionalization have influenced the composition of their residential patient populations.

Methods

Data from the Dutch UTOPIA-study (UTilization & Outcome of Patients In the Association of Dutch residential care providers) and the Italian PROGRES-study (De Giralomo et al, 2002; De Giralomo et al, 2005) were used.

Results

Dutch residents were more likely to suffer from substance or alcohol abuse than the Italian residents. The latter were more likely to suffer from schizophrenia or a related disorder, less likely to have experienced admissions to a mental hospital and showed an overall shorter duration of stay in residential care facilities. Contrary to our expectations Dutch residents, who still have good access to long stay beds in mental hospitals, are not less disabled than Italian residents. Finally, the number of beds in residential care facilities per 10.000 inhabitants in the Netherlands is twice (6) as high as in Italy (3).

Conclusions

The Italian and Dutch deinstitutionalization processes have resulted in a different availability in the number of residential beds. However, it did not influence the overall level of functioning of both residential populations.

Key words - deinstitutionalization, residential facilities, schizophrenia.

Declaration of interest - An unconditional grant was received from the Alliance of the 22 Dutch independent residential care providers.

Introduction

The long-term mentally ill people living in residential facilities have largely been neglected in recent mental health services research, with some exceptions (Lelliot, Audini, Knapp et al, 1996; Leff & Trieman, 2000). Therefore, there is a lack of information about their social and clinical characteristics and the quality of housing and services provided. However, the interest in this issue is increasing. The Italian PROGRES-study (De Giralomo, Picardi, Micciolo et al, 2002; De Giralomo, Picardi, Santone et al, 2005) has made a large-scale attempt to characterize all residential care facilities and their residents. A comparable study in the Netherlands (the so called UTOPIA-study: UTilization & Outcome of Patients In the Association of Dutch residential care providers) started in 2006 and allows for a comparison of data.

Both in Italy and the Netherlands deinstitutionalization set off in the second half of the 20th century. In 1978 Law 180 initiated the replacement of mental hospitals with non-hospital facilities in Italy (De Giralomo & Cozza, 2000), whereas in the Netherlands residential care facilities were developed alongside mental hospitals (Wiersma, Kluiter, Pijl et al, 2002). This difference in development might have led to a different residential population in such facilities. The aim of this report is to compare the Italian and Dutch residential population on socio-demographic, clinical and care characteristics. We expect Dutch residents to be less disabled than the Italian residents, because of the greater availability of, and access to long stay beds in mental hospitals in the Netherlands.

Methods

In 2006, approximately 14 beds per 10,000 inhabitants were available in mental health services in the Netherlands. These mental health services roughly provided two places per 10,000 inhabitants in associated residential care facilities in the community as well. There were also 22 independent residential care facilities, which operate independently from mental health services, which approximately provided another three residential places per 10,000 inhabitants. Seven of these 22 Dutch independent residential care providers participated in this study. The sample used in this study was selected on the completeness of the provided client administration data.

Data on 1656 residents, equivalent to 71% percent of their residential population, included socio-demographic data (gender, age, civil status, former place of residence), clinical diagnosis, GAF scores, age of first contact with mental health services, and history of mental health care use (length of stay in a residential facility, any former admissions to a mental hospital). 9.7% in the Netherlands – Table I). Manual searches in medical files were made in case of missing data. Compared to the total patient population of the 22 independent residential care providers (5548 residents), this sample had more often been referred from a mental hospital (58% vs. 54%) and was slightly older (mean age 48 years (SD 15.5) vs. 46 years (SD 15.3). The sample did not differ from the total patient population on other characteristics, such as sex, clinical diagnose, GAF-scores, and length of stay in a residential facility. Therefore we consider the sample as fairly representative. Chi-square contingency tables and an independent sample t-test for GAF scores were used to compare the Dutch and Italian residential population.

Results

The catchment area of this sample of Dutch residential care facilities consisted of 5298 km2 with six residential beds for every 10,000 inhabitants, which is twice as high compared to Italy, with an overall ratio of three (De Girolamo et al, 2002).

Socio-demographic characteristics

The male/female-ratio is approximately 2:1, with males being younger than females (mean = 45.8 *vs.* 52.1 years in the Netherlands, and 48.6 *vs.* 50.9 years in Italy) in both countries. The largest age group consists of patients who are between 50 and 64 years of age. In the Netherlands more patients under 30 years live in these facilities (15.3% in the Netherlands and 8.4% in Italy). More than 90% of residents in both countries are either never married or divorced; Dutch residents have a higher divorce rate, especially when gender is taken into account (25.3% of all female Dutch residents is divorced). The residential care facilities accommodate a large group of former mental hospital patients (45.2% in Italy and 58.2% in the Netherlands). More Italian residents have been referred from another residential facility to the current facility (23.8% in Italy and 9.7% in the Netherlands-Table 1 on the next page).

Table 1 A comparison of Dutch and Italian residents in residential care facilities in the community

	The Netherlands (n=1656)		**Italy**[1] (n=2962)		**Test**
	%	(n)	%	(n)	χ^2, df, p
Socio-demographic characteristics					
Gender					
• male	61.2	(1014)	63.2	(1873)	1.79 df=1 p=0.18
• female	38.8	(642)	36.8	(1089)	
Age groups					
• 16-29	15.3	(252)	8.4	(251)	58.7 df=4 p<0.001
• 30-39	15.0	(248)	19.2	(570)	
• 40-49	22.8	(376)	21.8	(647)	
• 50-64	32.4	(535)	34.3	(1015)	
• 65+	14.6	(241)	16.2	(479)	
Civil status (n=1561)					
• Never married	77.8	(1214)	82.0	(2418)	52.1 df=3 p<0.001
• Separated / divorced	17.0	(265)	10.6	(313)	
• Widowed	3.3	(51)	2.9	(86)	
• Currently married	2.0	(31)	4.4	(131)	
Former place of residence (n=1465)					
• On their own / Family residence	26.5	(389)	24.6	(715)	138 df=3 p<0.001
• Other residential care facility	9.7	(142)	23.8	(692)	
• (Forensic) mental hospital/long stay ward	58.2	(852)	45.2	(1310)	
• Other (e.g. Salvation Army, jail, homeless)	5.6	(82)	6.4	(185)	
Clinical characteristics					
Diagnostic categories of residents (n=1512)					
• Schizophrenia and related disorders	58.9	(890)	74.6	(2001)	121 df=3 p<0.001
• Bipolar disorders	5.0	(76)	4.5	(120)	
• Other (e.g. organic disorders, mental retardation eating disorders, pervasive developmental disorders)	34.1	(515)	20.0	(537)	
• Primary substance or alcohol abuse	2.0	(31)	0.9	(24)	
Comorbid substance/alcohol abuse (n=1481)	29.2	(432)	4.6	(135)	537 df=1 p<0.001
GAF scores (n=792), mean (sd.)[2]	49.1	(11.5)	43.6	(17.9)	8.2,df=3752,p<0.001
Median	50.0		42.0		
Age of first contact with mental health services (years) (n=778)					
• < 18	14.7	(114)	21.2	(624)	132 df=3 p<0.001
• 18-29	44.1	(343)	55.7	(1643)	
• 30-39	20.1	(156)	15.6	(459)	
• 40+	21.2	(165)	7.6	(223)	

	The Netherlands (n=1656)		Italy[1] (n=2962)		Test		
	%	(n)	%	(n)	χ^2, df, p		
Characteristics of care							
Length of stay in RF (years)[3]							
• ≤ 1	19.8	(324)	24.5	(695)	234	df=3	p<0.001
• 1-3	22.9	(375)	40.3	(1147)			
• 3-6	22.4	(366)	17.0	(482)			
• 6+	34.9	(570)	18.3	(522)			
Former admissions to a (forensic) mental hospital, % yes (n=1275)	89.9	(1146)	54.8	(1577)	521	df=1	p<0.001

[1] Data derived from De Girolamo et al (2005)
[2] T-test was performed
[3] The Dutch categories for 'length of stay in RF' are slightly different from the Italian categories, which are '< 1 year', '1-3 years', '4-5 years' and '6+ years' respectively. Still, a comparison is made to give an impression of the trend in the data

Clinical characteristics

Almost three quarters of the Italian residents are diagnosed with schizophrenia or a related disorder, while in the Netherlands this is the case for nearly 60% of the residential population. In both countries, a large part of residents with a clinical psychiatric diagnosis and comorbid substance or alcohol abuse is suffering from schizophrenia (54.7% and 57.9% respectively). However, the total number of people suffering from (comorbid) alcohol or substance abuse is much higher in the Netherlands. Nevertheless, the level of functioning in terms of GAF scores is higher for the Dutch population. The median age of Dutch residents at first contact with mental health services was four years higher (26 years, mean=29.3) than that of Italian residents at first mental health services contact (22 years; De Girolamo et al, 2005).

Characteristics of care

The majority of Dutch residents (57%) live more than 3 years in the current residential facility, while in Italy this applies to about one third of the residential population. Dutch residents were more often admitted to a mental hospital in the past.

Discussion

Although the data were retrieved from client administration systems and medical files, and were not gathered under strict systematic research conditions, they provide valuable information about social and clinical characteristics of the Dutch residential population in the community and allow for a global comparison with a corresponding population in Italy. Even though all but one of the characteristics we compared were significantly different (caused by the relatively large cohorts), the Dutch and Italian residential populations are quite similar.

Nevertheless, the most striking difference was the relatively low rate for primary and comorbid substance or alcohol abuse in Italy. This may indicate a more restrictive policy in the Italian residential facilities in admitting patients with dependency problems (De Girolamo et al, 2005).

Another difference was the higher percentage of residents diagnosed with schizophrenia or a related disorder in Italian residential facilities. However, from this it cannot be concluded that the Italian residents are more severely disabled, because the Dutch residents more often experienced an episode of hospitalization in the past. The comparison of overall mean GAF scores of both populations showed a significantly lower level of functioning of Italian residents compared to the Dutch residential population. However, since both GAF scores were between 40 and 50, they do not seem to imply a clinically relevant difference.

Although Dutch residents were overall younger than Italian residents, their length of stay in a residential facility is longer. This may indicate a higher turnover rate in the Italian residential facilities, perhaps pressured by the much lower number of available places. In addition, Italian residents might have a more effective or available social support system, which makes discharge more likely. Especially, the role of the family as a support system might be much stronger in the Italian culture than it is in the Netherlands. We expected the Italian residents of residential facilities to be more disabled than the Dutch residents, because mental hospitals in the Netherlands still offer long stay facilities for the most disabled patients. However, we did not find evidence to support this expectation.

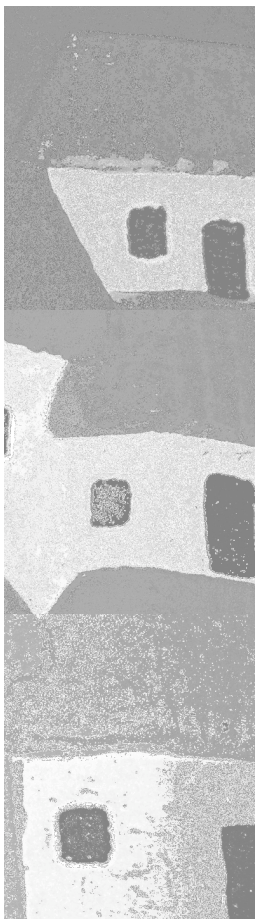
The overall ratio of available residential places per 10,000 inhabitants (three residential places per 10,000 inhabitants) is different from the sample ratio (six

residential places per 10,000 inhabitants). This difference can be explained in the following way: independent residential care facilities do not operate in some Dutch mental health regions, while the number of inhabitants of these regions is included in the calculation of the overall ratio. For our sample, we have corrected the ratio for this by only including the number of inhabitants of the catchment areas of the seven participating independent residential care facilities.

Conclusion

During the process of deinstitutionalization the mental hospitals in Italy were replaced by residential care facilities, while in the Netherlands these residential facilities were developed alongside the mental hospital. In the Netherlands, this has not led to a substantial decrease in the total number of available psychiatric hospital beds compared to other European countries like England, Sweden or Spain (see e.g. Priebe, Badesconyi, Fioritti et al, 2005). Moreover, the number of available beds per 10,000 inhabitants in residential care facilities is much higher than in Italy. However, the difference in availability of mental hospital beds between Italy and the Netherlands has not led to major differences in the overall level of functioning between their residential populations, according to their overall mean GAF-scores.

3



Supported Housing and Supported Independent Living in The Netherlands, with a comparison with England

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Abstract

Research into community housing programs for people with severe mental illness is underexposed. The Dutch UTOPIA study describes characteristics of their service users, which may predict their allocation to either supported housing or supported independent living programs. Additionally, a comparison is made with English studies.

119 Care coordinators of Dutch residential care institutes and 534 service users participated in a cross-sectional survey which includes socio-demographic data, clinical data, measures of functioning, needs for care and quality of life.

Differences between Dutch residents and independent living service users were small, making predictions of care allocation difficult.

This similarity suggests a possible lack of methodical assessment in the allocation procedure of people who are eligible for residential housing or independent living programs. This is largely comparable to the English situation. In comparison with their English counterparts, Dutch service users have more met needs and are more engaged in occupational activities.

Key words - community mental health care, residential care, supported housing, supported independent living, care allocation.

Introduction

In Europe, people with severe mental illnesses (SMI) are more and more allocated to community housing programs, such as supported housing and supported independent living (Fakhoury, Murray, Shepherd et al, 2002). Supported housing includes permanent and supervised housing in residential facilities, which are owned by a mental health service in the community. People who are not related to each other, but all cope with impairments due to psychiatric problems live together in these facilities. Supported independent living provides support in the home of an individual with SMI, who lives on his own or with a partner, friend or family members.

Research into these programs and the characteristics, functioning and quality of life of its' service users is limited. Recently, Priebe, Saidi and Want et al (2009) conducted a study into different housing programs in England. They found a considerable overlap of characteristics of service users and care provision between housing services of supported housing and supported independent living. This brings the current system of allocation of people with SMI to such housing programs up for discussion. Priebe et al (2009) raise the question whether their care allocation system benefits from the flexibility to provide the right care to individuals, taking their specific situation and needs for care into account, or that the system lacks objective criteria. These criteria are needed to guarantee a methodical and structural assessment of potential service users with a certain amount of objectivity in allocating people to an appropriate level of care.

The present study (which is part of the UTOPIA study; De Heer-Wunderink, Caro-Nienhuis, Sytema et al, 2008), including a random sample of 119 Dutch care coordinators and 534 service users of community housing programs, looks into the allocation system of Dutch community housing programs. This study describes the socio-demographic and clinical characteristics of service users of supported housing (residential care) and supported independent living programs, their prediction of allocation to either type of care and the association between type of care and social participation, needs for care and quality of life. A comparison is made with two English studies (Priebe et al, 2009; Slade, Leese, Cahill et al, 2005) in order to discuss the (dis)similarities between both countries which differ greatly in process and outcome of deinstitutionalization.

Methods

Setting

In The Netherlands, 21 Dutch Regional Institutes for Residential Care (RIRC, Dutch acronym RIBW) provide supported housing and supported independent living in the community for people with SMI. The Exceptional Medical Expenses Act funds the care provision of RIRCs. The eligibility of an individual for these services is assessed by the so-called 'Center for Indications for Care' (CIC). The application for supported housing and supported independent living can be carried out by the person concerned or by any health care professional, e.g. a general practitioner (GP) or a psychiatrist. The CIC gathers information about the individual applicant and his situation, e.g. by interviewing this person and retrieving information from his GP or specialist. Supported housing is allocated when the CIC concludes that the applicant has a psychiatric impairment, and needs a protective living environment and/or permanent supervision. Supported independent living is allocated when the person suffers from moderate or severe impairments in the area of social independence, psychiatric functioning, cognitive skills or moderate or severe behavioral problems, without the need for a protective living environment and permanent supervision.

RIRCs have explicitly distinguished themselves from hospital-based long stay facilities in their focus of care. Where the latter focus primarily on reducing psychiatric symptoms, the first are mainly concerned with the service users' daily living, rehabilitation and participation in society. This reflects on their community housing facilities, which are mainly one-family homes, providing single bedrooms and a shared living room, kitchen and bathroom for (in general) four residents per home. Furthermore, the number of small-scale housing facilities, especially individual apartments for one or two (sometimes related) individuals, has increased in the last five years. RIRCs also manage day centers, sheltered employment projects and offer job coaching to stimulate occupational participation.

All residents receive support from a care coordinator, who is skilled in the Psychiatric Rehabilitation Approach (Anthony, Cohen, Farkas et al, 2002; Anthony & Farkas, 2009). The most important aspects of this approach in this context are the equality of the therapeutic relationship and the special focus on goal setting, which is guided by the service users' own wishes and choices. RIRCs, with one exception, do not exclude people who cope with substance abuse. This group of service users and also other groups with specific problems such as deaf people with SMI, children under 18, people

suffering from autism and mothers with children, are often provided with care in specific facilities and/or by care coordinators who have been trained to work with these people.

In 2007, 11,427 Dutch people received supported housing in the community (Van Hoof, Knispel, Van Wijngaarden et al, 2009). Roughly half of them received this type of community care from mental health institutes (mostly former mental hospitals); the other half received supported housing in the community from RIRCs. In addition, the RIRCs also provided support and counseling to 6,797 people in supported independent living.

All RIRCs were invited to participate in a cross-sectional survey of a random sample of care coordinators and their patients, but 16 of the 21 institutes actually took part in the study. All care coordinators met the following criteria: employed for at least 24 hours per week for at least one year to guarantee familiarity with the organization and the way of counseling (trained in the Psychiatric Rehabilitation approach; Anthony et al, 2002; Anthony & Farkas, 2009), and involved with the day-to-day care of the service users. From a total of 1,275 care coordinators, 119 (9%) were selected to ensure a minimal mean number of 40 participating service users per RIRC. They initially approached 1,432 service users of whom 818 (57%) gave their written informed consent. Only participants with complete data records (n=534, 65%) were included in this study. Participants and non-participants did not differ on gender, age, type or length of care / support (RIRC) in years, psychiatric diagnosis, comorbidity of substance abuse or a personality disorder.

The study was discussed with the secretary of the medical ethics committee of the University Medical Center Groningen and considered to not require formal approval by the full committee.

Instruments

Service users filled in a socio-demographic data questionnaire and the Manchester Short Assessment of quality of life (MANSA; Priebe, Huxley, Knight et al, 1999). The MANSA consists of 4 objective questions to be answered with yes or no and 12 subjective questions rated on a scale between 1 (= couldn't be worse) and 7 (= couldn't be better) about satisfaction with life as a whole, friendships, accommodation, the financial situation etc. In the present study, the mean item score of the 12 subjective questions is used, where a higher mean item score reflects a

better quality of life. Cronbach's alpha of the satisfaction ratings is 0.74 (Priebe et al, 1999). Clinical data were gathered from the care coordinator.
Level of functioning was determined by the Health of the Nation Outcome Scales (HoNOS; Wing, Beevor, Curtis et al, 1998), comprising 12 domains of functioning which are rated by care coordinators on a scale between 0 (=no problem) to 4 (= (very) severe problem). The total mean HoNOS score, which is used in this study, is the mean sum of the scores on 12 domains. Intraclass correlation coefficients for the individual items and the total score were between 0.74 and 0.88, except for the item of aggression (icc=0.61) (Wing et al, 1998). The service users were divided into groups based on their level of functioning (based on the division used by Parabiaghi, Barbato, D'Avanzo et al, 2005): 1) a group with no to mild problems (maximum score 2 on at least one item): 38%; 2) a group with (very) severe problems (score 3 or 4 on at least one item): 62%.

The Camberwell Assessment of Need Short Appraisal Schedule (CANSAS; Phelan, Slade, Thornicroft et al, 1995) was used to establish care coordinator rated needs for care. It comprises 22 items concerning social and health needs. Needs are rated on a three point scale: 0 = no need, 1 = a met need (a problem which is (at least largely) solved by an intervention) and 2 = an unmet need (a problem has not been solved, either because there is no intervention or the applied intervention is not sufficient). The total number of needs (maximum 22) is the sum of all met and unmet needs. Inter-rater correlation and test-retest correlation of the total number of needs were 0.99 and 0.78 respectively as assessed by Phelan et al (1995). Housing needs were not taken into account since most people in residential care had a met need. Met and unmet needs were grouped into the four following domains: 1) Activities of Daily Living (food, self-care and looking after the home); 2) Mental Health Care (physical health, psychotic symptoms, information on medication, psychological distress, safety to self and others, alcohol and drugs); 3) Rehabilitation (daytime activities, company, intimate relationships, sexual expression and child care); and 4) Services (education, telephone, transport, money and benefits). All care coordinators were trained in the use of these instruments.

Data analysis

Univariate tests were performed to establish statistically significant differences between residents in supported housing and people in supported independent living programs. Associations between normally distributed variables were determined by Pearson's correlation coefficient; the Kendall's Tau-b correlation coefficient was

calculated for associations between one or more non-parametric variables. Logistic regression analysis was carried out to determine associations between patient characteristics and the type of care received. Only variables that showed significant differences between groups in the univariate tests were included in the logistic model.

Logistic regression analysis was also used to determine whether level of functioning ((very) severe functional problems *v.* no to mild functional problems) was associated with differences in employment status, type of housing (supported housing or supported independent living), the nature of met and unmet needs for care and satisfaction (as measured with the MANSA) with life as a whole, daily activities, physical and mental health status, and the relationship with partner and family.

Data from the study of Priebe et al (2009) and of Slade et al (2005) were used to compare Dutch residents and Dutch service users receiving supported independent living to their English counterparts. Dutch independently living service users were compared to English people receiving so-called 'floating support' (Priebe et al, 2009). Although different terms are used, these housing programs seem to be comparable. They both seek to maintain an independent living situation and to develop living skills for people with SMI. However, supported independent living is provided for an indefinite period of time, whereas floating support is restricted to a period of -in general- less than two years. Since a large part of Dutch people in supported independent living receives this support for less than four years, the actual differences in the length of care provision between these programs are probably relatively small. Floating support will be further referred to as supported independent living. The study of Slade et al (2005) concerns a sample of service users of community mental health teams, who are similar to the participants in the study of Priebe et al (2009) in supported housing and supported independent living on age and diagnosis of schizophrenia, but not on gender (participants in the study of Slade et al are more likely to be female).

Results

Socio-demographic and clinical characteristics

In The Netherlands, residents in supported housing are more often male (χ^2=9.632, P=0.002) and lower educated (χ^2= 15.933, P<0.001) than service users in supported independent living programs (Table 1 on the next page).

Table 1 Socio-demographic and clinical characteristics of residents in supported housing and service users receiving supported independent living

	The Netherlands		England[1]	
	Supported housing (n=332)	Supported independent living (n=202)	Supported housing (n=175)	Supported independent living (n=66)
Males, %	62	48	74	71
Age, mean (sd)	43.1 (14.6)	43.8 (12.1)	43.9 (11.8)	43.1 (12.5)
Never married, %	71	72	95	98
Education, %				
• ≤ primary school	24	10	-	-
• lower/moderate vocational	56	59	-	-
• higher voc./(pre)university	20	30	-	-
Diagnosis, %				
• Schizophrenia	50	31	59	52
• Mood / anxiety disorders	22	36	19	26
Substance abuse, %	31	21	29	26
Personality disorder, %	35	41	-	-
Total HoNOS score, mean (sd)	11.7 (6.0)	11.6 (6.7)	-	-
Length of stay/provided support, %				
• 0-4 years	49	58	-	-
• 4 to 6 years	17	19	-	-
• > 6 years	34	23	-	-
Occupational activity, %				
• Unemployed	45	42	-	-
• Paid employment	7	12	3	8
• Voluntary/sheltered employment[2]	48	46	28	16
Attending day centre, %	47	32	42	47
Spoken to a friend in the past week, %	69	80	-	-
Needs (met/unmet needs)				
Total mean number of met/unmet needs	6.7/1.6	5.5/1.8	4.4/3.1	4.5/3.0
Domains of need, mean number met/unmet:				
• Activities of Daily Living	1.3/0.2	0.9/0.2	0.8/0.5	0.7/0.5
• Mental Health Care	2.5/0.6	2.1/0.6	2.1/0.9	2.4/0.7
• Rehabilitation	1.3/0.7	1.4/0.8	0.7/1.1	0.5/1.4
• Services	1.6/0.2	1.1/0.2	0.9/0.6	0.8/0.5
MANSA mean item score (sd)	4.5 (1.3)	4.3 (1.2)	4.3 (1.0) (n=101) **	4.3 (1.0) (n=101) **

[1] Data derived from Priebe et al (2009), except for variables marked with ** data derived from Slade et al (2005).
[2] From Priebe et al the number of patients involved in 'occupational activities provided by the service' were added to this category for comparability with the Dutch patients. English 'involvement in community activities' was not taken into account, because the actual activities concerned were not described and did not seem to involve either paid, supported or voluntary employment.
- Data are not available in the reported studies.

Residents in supported housing are also more likely to be diagnosed with schizophrenia or related disorders (χ^2=17.588, P<0.001), to cope with substance abuse (χ^2=6.647, P=0.010) and to reside in the current RIRC for more than six years (χ^2=8.005, P=0.005). People in supported independent living are more often diagnosed with mood and anxiety disorders (χ^2=13.261, P<0.001). Surprisingly, the mean total HoNOS score is not different between both groups, and neither are the proportions of people with (very) severe problems (63% *v.* 57%).

A logistic regression analysis (supported housing *v.* supported independent living) revealed that being male (OR 1.644, P=0.011), a lower educational level (OR 2.524, P=0.001), a diagnosis of schizophrenia (OR 1.742, P=0.006) and length of care for more than six years (OR 1.534, P=0.049) significantly predicted allocation to supported housing. However, the odds ratio's indicated that the differences between both groups were relatively small.

Social participation, needs for care and quality of life

More than half of Dutch residents in supported housing have paid or sheltered/voluntary employment, which is more or less similar to the independently living service users. Nearly half of the residents attend a day centre, where this is only the case for a third of the independently living service users (χ^2=11.355, P=0.001). As for social contacts, residents in supported housing are less likely to report a friendly contact in the past week than independently living service users (χ^2=6.905, P=0.009).

The difference between the two groups as to met needs was statistically significant: residents were assigned a higher total mean number of met needs (Mann Whitney Z=-5.470, P<0.001), as well as a higher total mean number of met needs for three of the four domains. In the area of Rehabilitation the total mean number of met needs did not differ. No differences were found between residents and independently living service users as to the total mean number of unmet needs and the total mean numbers of unmet needs for the four separate domains.

The quality of life as measured with the MANSA did not differ much between both Dutch groups, although the total mean item score reported by residents was somewhat higher (*t*=2.032, df=532, P=0.043). On the 7-points-scale only a slightly higher than average satisfaction with various aspects of life was reported. Quality of life appeared to be negatively associated with unmet needs (Kendall's Tau-b=-0.265,

P<0.001), which is in agreement with other studies (Wiersma & Van Busschbach, 2001; Slade, Leese, Ruggeri et al, 2004).

A logistic regression analysis revealed that all these factors (attending a day centre (OR 1.931, P=0.001), number of met needs more than total mean number of met needs (OR 2.533, P<0.001) and a higher quality of life (OR 1.529, P=0.026) were significantly associated with supported housing. Having had a friendly contact in the past week was significantly associated with independent living with support (OR 1.762, P=0.011).

A comparison between the two groups of Dutch service users revealed that users with (very) severe problems (score 3 or 4 on at least one HoNOS item) differ from those with no to mild problems (maximum score 2 on at least one item) on the number of unmet as well as met needs. The first were more likely to have a higher number of unmet needs in the domains of Activities of Daily Living (mean 0.23 (sd 0.575) *v.* mean 0.04 (sd 0.219); OR=2.604, P=0.014), Mental Health Care (mean 0.81 (sd 1.095) *v.* mean 0.17 (sd 0.537); OR=2.400, P<0.001) and Services (mean 0.28 (sd 0.564) *v.* mean 0.08 (sd 0.305); OR=1.994, P=0.019). They were also more likely to have more met needs in the domains of Mental Health Care (mean 2.50 (sd 1.345) *v.* mean 2.20 (sd 1.179); OR=1.210, P=0.044) and Services (mean 1.56 (sd 1.228) *v.* mean 1.15 (sd 1.084); OR 1.296, P=0.012). No differences were found regarding employment status, type of housing (supported housing or supported independent living), and satisfaction (as measured with the MANSA) with life as a whole, daily activities, physical and mental health status and the relationship with a partner and their family.

Dutch and English residents and people in supported independent living programs compared

Table 1 shows that English people in supported housing - compared to the Dutch - are more often male (χ^2=8.04, P=0.005), of equal age, more often unmarried (χ^2=38.7, P<0.001), less likely to be involved in paid (χ^2=4.06, P=0.044) and voluntary or sheltered employment (χ^2=19.8, P<0.001) and equally active in attending a day centre. They are more often diagnosed with schizophrenia (χ^2=3.86, P=0.050), have a comparable total mean number of needs, but a higher number of unmet needs[1]. The

[1] A statistical test could not be performed, because standard deviations of the total mean number of (un)met needs in the study of Priebe et al (2009) were not reported.

ratio between met and unmet needs for the four separate domains shows that English residents have less met needs and more unmet needs in all these areas.

Differences between English and Dutch service users receiving supported independent living tend in the same direction: the first are more likely to be male (χ^2=10.8, P=0.001), less often married (χ^2=20.9, P<0.001), equally involved in paid employment but less likely to be involved in voluntary or sheltered employment (χ^2=29.2, P<0.001), more likely to attend a day centre (χ^2=4.73, P=0.030), more often diagnosed with schizophrenia (χ^2=8.9, P=0.003), but are of the same age, and have roughly the same total number of needs although more unmet needs [a]. Regarding the ratio between met and unmet needs for the four separate domains, Table 1 shows that in the domain of Mental Health Care English independently living service users have slightly more met needs than their Dutch counterparts and a comparable number of unmet needs. The difference in quality of life between both groups is small.

Discussion

The results of the present study, focusing on the (dis)similarities between people with SMI in supported housing and supported independent living programs in The Netherlands, reveal that differences between these two groups are much smaller than one would expect. Participation in occupational activities, attending a day centre, number of (unmet) needs and quality of life do not differ greatly. This calls the Dutch allocation system to housing programs into question: are we dealing with a flexible system that contributes to positive outcomes for individuals, or is there a lack of methodical assessment of people with SMI when applying for either supported housing or supported independent living in the community? For instance, more than one third of Dutch residents in supported housing have at most mild functional problems according to their HoNOS scores. This suggests that at least a part of these people might currently receive a higher level of care than is actually required, and perhaps also wished for by residents themselves. This is a pressing issue, taking the long and persisting waiting lists for this type of care into account.

We did find differences between the number of unmet and met needs of Dutch service users with different levels of functioning, regardless of type of housing program. In the domains of Mental Health Care and Services, people coping with (very) severe problems not only have more met needs than people with no to mild problems, but also more unmet needs. Although care is provided, some needs in these domains

remain difficult to meet. For example, prescribed antipsychotics can reduce psychotic symptoms, but at the same time can cause hindering side effects. In the area of Activities of Daily Living, people with severe impairments also have more unmet needs.

The composition of the service user population in supported housing and supported independent living in England differs to some extent to that in The Netherlands, e.g. with respect to gender (more males), civil status (more persons who have never been married) and diagnosis (more persons with schizophrenia). This suggests that the English service users possibly are more similar to the long stay population from the closed or reduced mental hospitals. Deinstitutionalization in The Netherlands has taken place at a much slower pace, if at all, and has resulted since the nineties in an increase of small-scale residential facilities in the community. These facilities are open not only for people residing in the mental hospital but also for those who never entered such a long stay trajectory. Despite these different deinstitutionalization processes, the overall effect on the people with SMI in housing programs seems small. However, we did find differences in the extent to which English and Dutch service users participate in occupational activities. In The Netherlands, participation rates are much higher. This might be a consequence of the similarity of English service users - more than the Dutch service users - to the long stay population of mental hospitals. Furthermore, Dutch governmental policy in the 90's created possibilities for RIRCs to invest in the development of projects concerning occupational activities. This has resulted in a wide range of projects with different levels of structure and demands for participation offered by RIRCs, e.g. day centers, sheltered employment projects and job coaching. It is not clear if English service providers have similar facilities.

Although English and Dutch service users in supported housing and supported independent living have a comparable total number of needs, the English have a lower number of met needs. Only in the Mental Health Care domain, English people in supported independent living have slightly more met needs. This can be seen as a small but further confirmation of the more chronic nature of the psychiatric problems of English service users. Another (perhaps additional) explanation can be the policy of Dutch RIRCs to distinguish themselves from the mental hospital, in not providing psychiatric treatment. This may have consequences for the way psychiatric problems are dealt with by care coordinators, who perhaps lack skills to observe and monitor these problems properly. However, differences in unmet needs for this domain are negligible. Overall, it seems that Dutch community care may be more able to address

the needs of their service users, though more information is needed about the level of functioning of the English service users to substantiate these findings.

One should be aware of some limitations in the reported studies. Our study and those of Priebe et al (2009) and Slade et al (2005) have a cross-sectional design, which entails that relationships between cause and effect cannot adequately be determined. Furthermore, the participants in the study of Slade et al are slightly different (more females) from that in the study of Priebe et al.

Comparisons between housing programs in different countries are difficult. Descriptions of residential facilities and the care they provide vary in their characteristics and terminology. For example, in the present study the Dutch supported independent living program is compared to the English floating support program. They seem to be similar programs, except for the latter program to be limited to a fixed period of time whereas the first -in principle- is provided indefinitely. This could be a limitation to the strength of this comparison. To further establish the (dis)similarities between quality and nature of the community housing programs in The Netherlands and England (and in other countries that experienced deinstitutionalization) in depth research into among other things the independency of living space (e.g. in The Netherlands all residents in supported housing have their own bedroom), autonomy of residents and the scale of residential homes is needed. In these comparative studies, it is also important to take into account some contextual factors, such as social policy regarding employment of people with SMI, economic factors and access to healthcare.

Finally, Dutch hospital based mental health institutions also provide supported housing and supported independent living programs in the community, but these facilities were not taken into account. A comparative study between supported housing and supported independent living provided by hospital-based facilities versus RIRCs is needed in the future.

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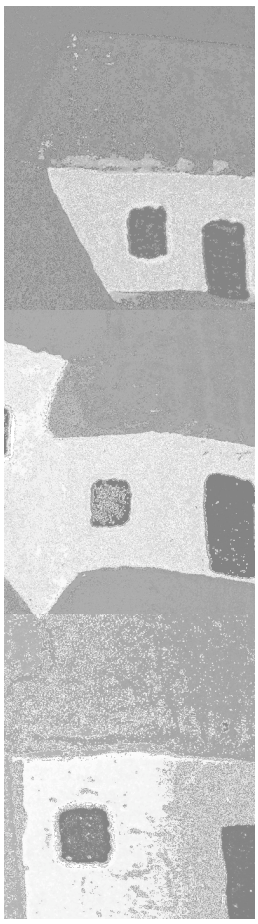

Social Inclusion of People with Severe Mental Illness Living in Community Housing Programs

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Charlotte de Heer-Wunderink, Ellen Visser, Annemarie-Caro-Nienhuis, Sjoerd Sytema, Durk Wiersma

Psychiatric Services: under review

Abstract

Objective

The levels of social inclusion of service users of two types of psychiatric community housing programs were investigated and compared.

Methods

We conducted a large scale cross sectional survey that included service users of community housing programs (N=255) and their key workers (N=75). Data on social inclusion, i.e. participating in activities, receiving and making visits and vocational participation, were collected through a service user diary. We performed multivariate regression analyses with the social inclusion variables as the dependent variables and type of housing program (i.e. supported independent living vs. supported housing) as the independent variable.

Results

Independently living service users are more likely to be socially included, in terms of activities and visits, than people residing in supported housing programs. The type of housing program was not associated with vocational participation.

Conclusions

Although independently living service users are more likely to be socially included, they are similar to people in supported housing as regards vocational participation. It seems that for both service user groups, it is important to make specific interventions or programs in this area (such as Supported Employment) more readily available.

Introduction

Mental health policy across Western European countries is focused on providing long term psychiatric care in community-based rather than hospital-based facilities. This policy aims to rehabilitate people with severe mental illness (SMI) (Anthony, Cohen, Farkas et al, 2002) and to enhance their chances for social inclusion. Studies show that when people with SMI reside in more normal surroundings (e.g., a family home instead of a hospital ward), this has a normalizing effect on their daily life. For instance, they show improved (social) functioning (Fakhoury, Murray, Shepherd et al, 2002), are less likely to be hospitalized (Rog, 2004; Shepherd, Muijen, Dean et al, 1996), experience a better quality of life (Shepherd, Muijen, Dean et al, 1996; Priebe, Hoffmann, Isermann et al, 2002; Nelson, Sylvestre, Aubry et al, 2007), and report higher satisfaction with care (Fakhoury, Murray, Shepherd et al, 2002; Shepherd, Muijen, Dean et al, 1996; Newman, 2001).

In the Netherlands, two types of community housing programs are distinguished. The first is supported housing, which enables people with SMI to live in the community but in a residential facility. The other program is supported independent living, which offers independently living people with SMI psychosocial support in their own home. Both programs generally differ in social context (i.e. living in a facility with other service users vs. living in your own home), level of staff supervision and frequency of therapeutic contact. However, earlier studies in the Netherlands and in England revealed that their service users are quite similar in terms of socio-demographic and clinical characteristics (De Heer-Wunderink, Visser, Caro-Nienhuis et al, 2011; Priebe, Saidi, Want et al, 2009). This pressing issue raises the question whether they differ in other respects, for example, in terms of social inclusion. Due to the recent cuts in budgets, mental health services need to reconsider their care provision and deliver the same amount and quality of care against fewer costs. This entails replacing the most expensive, institutionalized type of community care for a cheaper alternative. However, given that service users themselves also stress the importance of independence, autonomy, and the need to be socially included (Thornicroft, Bebbington & Leff, 2005; Seilheimer & Doyal, 1996; Tanzman, 1993; Warren & Bell, 2000; Browne, Hemsley & St. John, 2008), such development should not necessarily be viewed in negative terms. Previous studies have indicated that social inclusion of people with SMI is far from successful. A large proportion spend a substantial amount of their time passive, sleeping or with self-care activities (Yanos & Robilotta, 2011; Eklund, Leufstadius & Bejerholm, 2009; Edgelow & Krupa, 2011). Psychiatric

community housing programs are probably one of the most important long-term interventions to take up this issue (Bigelow, 1998; Wong & Solomon, 2002). In 2009, the Dutch Mental Health Association published a report stating their aim for enhancing recovery and citizenship for people with SMI, of which housing is an important part. They described related aims, such as more consumer choice in housing, for shortening the care trajectory from hospital, to supported housing, to supported independent living programs, and to align more effectively the living environment of people with SMI to their needs. This national approach is in line with priorities stated in 2010 by the Federation of the European Academies of Medicine (FEAM) for European mental health care, which include tackling stigma and problems associated with employment for people coping with SMI (Fears & Höschl, 2011).

In the present study, we aim to gain insight into the social inclusion of service users of psychiatric community housing programs. We compare supported housing programs with supported independent living programs to establish if there is a relationship between housing program and level of social inclusion. We focus on three aspects of social inclusion: 'activities', alone and with others, 'visits' to and from other people and 'vocational participation'.

Methods

Setting

This study is part of the UTOPIA-study, a large-scale cross-sectional survey investigating Dutch Regional Institutes for Residential Care (RIRC, Dutch acronym RIBW). In the Netherlands, 22 RIRCs provide supported housing and supported independent living programs in the community for people with SMI. Supported housing is allocated to people with a serious psychiatric impairment, who need a protective living environment and permanent supervision. Supported independent living is allocated when someone has moderate or severe impairments in the area of social independence, daily living, psychological functioning, cognitive skills or moderate or severe behavioral problems, without the need for a protective living environment and permanent supervision. All key workers are trained in the Psychiatric Rehabilitation approach (Anthony, 2009).

The number of service users of Dutch RIRCs has increased rapidly in the past decade. Between 2006 and 2009, the number of available beds in supported housing

programs increased by 40% from 5,752 to 8,061 beds. The increase is not proportional to the decrease of conventional psychiatric hospital beds. This trend, also referred to as 'reinstitutionalisation', is taking place in other European countries as well (Priebe, Badesconyi, Fioritti et al, 2005). Supported independent living programs provided care to 6,935 people in 2006, compared to 9,943 people in 2009, an increase of 43%.

Instruments

Key workers (N=75) provided socio-demographic and clinical data and an assessment of the service users' level of functioning on the Health of the Nation Outcome Scales (HoNOS; Wing, Beevor, Curtis et al, 1998). The HoNOS consists of 12 domains of functioning that are rated on a scale between 0 (=no problem) to 4 (= (very) severe problem). The total mean HoNOS score is the mean sum of the scores on 12 domains. Service users were divided into four groups reflecting their level of functioning, according to Parabiaghi (Parabiaghi, Barbato, D'Avanzo et al, 2005): subclinical, mild, severe, and very severe problems. Key workers also filled out the Camberwell Assessment of Needs Short Appraisal Scale (CANSAS; Phelan, Slade, Thornicroft et al, 1995), to assess their view on service users' needs for care. Needs are rated for 22 items on a three point scale: 0=no need, 1=a met need, and 2=an unmet need. Key workers were trained to use these instruments by the researchers (CH-W, EV and AC-N).

A specific diary was developed for this study, with the help of four service users. The diary enabled service users to report their whereabouts for a week. (A copy is available from the authors). Each day was divided into four four-hour periods respectively ranging from 8.00–12.00 hrs, 12.00–16.00 hrs, 16.00–20.00 hrs to 20.00–24.00 hrs. For each period, service users were asked to record what they were doing, with whom, and where. Additionally, they rated each day on a scale from zero to ten (10=couldn't be better), measuring satisfaction with their daily life. A mean satisfaction score for each service user was calculated.

A random sample of 255 diaries was screened for 'activities', 'visits' and 'vocational participation (yes/no)'. 'Activities' only include task-like activities, e.g., doing groceries, being at work or at a day center and writing an e-mail. 'Visits' include all visits to or from other people. Social contacts with housemates were scored separately. Vocational participation includes paid employment, voluntary work and sheltered employment.

Sample

Sixteen RIRCs participated in this study between October 2007 and June 2008 and were asked to make a list of key workers who fulfilled the following criteria: involved in the day-to-day care for service users, employed for at least 24 hours per week, and engaged for more than one year, in order to guarantee familiarity with the organization and methods of support (Psychiatric Rehabilitation; Anthony, Cohen, Farkas et al, 2002). We randomly selected 192 key workers of which 119 (about 10% of the total number of key workers and 62% of the random sample) participated. They initially approached 1432 service users of which 818 service users (57%) gave written informed consent. Of the total number of participants, 677 (75%) filled out the diary. We randomly selected 255 diaries (38%) for analysis in the present study. Participating service users and non-participating service users did not differ on gender, age, psychiatric diagnosis, the presence of substance abuse and the presence of a personality disorder. The medical ethics committee of the University Medical Health Center in Groningen decided that the study was acceptable without an extensive formal approval procedure.

Data analysis

We used Stata/SE version 10.1 for statistical analyses. First, we conducted univariate analyses between socio-demographic, clinical and care characteristics and the variables concerning social inclusion (further referred to as 'the social inclusion variables'), i.e. the number of reported activities, the number of reported visits (all visits made and received by service users), and vocational participation (yes/no). Second, we performed multivariate regression analyses with the social inclusion variables as the dependent variables. In these analyses, type of housing program (supported independent living vs. supported housing) was included as the independent variable. We controlled for age, gender, educational level, psychiatric diagnosis, marital status, social support from partner/family/friends, substance use disorder, level of functioning, and unmet needs in the area of social contacts. In health services research, the environmental context – in this case the RIRC – also contributes to individual outcomes (Husum, Bjorngaard, Finset et al, 2010). Therefore, we used univariate and multilevel regression analyses to explore the association of service users' "RIRC membership" with social inclusion, and to assess the influence of "RIRC membership" on the relationship between type of housing program and level of social inclusion.

Results

Service user characteristics

The service users of both programs have a similar mean age, gender, civil status, and educational level (Table 1 on the next page). They are also comparable regarding the presence of a substance use disorder, a personality disorder, level of functioning (total mean HoNOS scores), and being admitted to a mental hospital in the past year. Service users of supported housing programs are more likely to cope with schizophrenia, while independently living service users are more likely to cope with anxiety disorders or depression. We also found differences concerning RIRC care (Table 1).

People in independent living programs have significantly less key worker support, and the nature of this support is more likely to be therapeutic instead of practical assistance. Almost nine out of ten people in supported housing are part of a shared household, of which only one in twenty lives with family or a partner. Only a quarter of independently living service users live with others, of whom one in two lives with family members or a partner. People in supported housing report more contacts with their housemates.

Social inclusion

The multilevel analysis revealed that "RIRC membership" was not associated with the social inclusion variables, and also did not significantly explain the variation of the relationship between housing program and social inclusion.

Independently living people report more activities, alone as well as with others (Table 2 on page 51). This result remained significant in a multivariate analyses with 'independent living (yes)' as the independent variable, explaining 19% of the variance in activity level (Adjusted R^2=.19, F(10,242)=6.79, p<.001; Beta=.25, t =4.16, p<.001). Both service user groups rarely participate in sports. As regards visits, again independently living service users are more active. Being in a supported independent living program explains 8% of the variance in the total number of visits (Adjusted R^2=.22, F(10,242)=3.30; Beta=.22, t=3.43, p=.001). Independently living service users receive more visits and are also more prone to visit others. In the area of vocational participation, however, we did not find significant differences between both programs. Neither in regard to the kind of vocational activity, nor as to hours per week spent on the activity. Only about one in three service users have a job of 16

Table 1 Socio-demographic, clinical, and care characteristics of service users of community housing programs (n=255)

	Supported housing (n=154)		Supported independent living (n=101)		Test	df	p
Socio-demographic characteristics							
Age, mean (sd)	43.8	(14.3)	44.5	(11.4)	t=-0.39	243.9	.694
Male, % (n)	57	(88)	52	(52)	χ^2=0.79		.375
Never married, % (n)	71	(77)	72	(48)	χ^2=0.00		.961
Education (n=254), % (n)					χ^2=4.41	2	.110
• none/only primary education	23	(35)	13	(13)			
• lower/senior vocational education	57	(87)	60	(60)			
• higher/university education	20	(31)	27	(27)			
Clinical characteristics							
Psychiatric diagnosis, % (n)							
• Schizophrenia	53	(81)	35	(35) **	χ^2=7.92	1	.005
• Anxiety/depression	20	(30)	40	(41) ***	χ^2=13.53	1	<.001
• Other	28	(43)	25	(25)	χ^2=0.01	1	.942
No substance use disorder present, % (n)	73	(112)	78	(79)	χ^2=0.98	1	.320
Personality disorder, % (n)	33	(51)	42	(42)	χ^2=1.89	1	.169
HoNOS total score, mean (sd)	10.8	(5.5)	11.7	(6.6)	t=-1.19	253	.230
HoNOS categories, % (n)					χ^2=1.30	3	.729
• no or secondary problems	8	(12)	12	(12)			
• moderate problems	33	(50)	30	(30)			
• severe problems	36	(56)	36	(37)			
• very severe problems	23	(36)	22	(22)			
Admitted to a mental hospital in the past year, % (n)	16	(25)	16	(16)	χ^2=0.02	1	.898
RIRC care and contacts							
Contact with (key) worker, total mean (sd)	4.3	(3.0)	1.7	(1.2) ***	Z=-7.35		<.001
• Visits from key worker, mean (sd)	2.7	(2.3)	1.1	(1.0) ***	Z=-5.47		<.001
• Contact by telephone with key worker, mean (sd)	0.3	(0.6)	0.3	(0.7)	Z=-0.58		.564
Nature of key worker support							
• Therapeutic support, mean (sd)	2.4	(2.1)	1.2	(1.0) ***	Z=-4.37		<.001
• Practical assistance, mean (sd)	1.4	(1.7)	0.5	(0.7) ***	Z=-4.34		<.001
• Being in a shared household, % (n)	88	(135)	23	(23) ***	χ^2=110.90	1	<.001
Total number of housemates, mean (sd)	7.0	(7.0)	2.9	(1.7) ***	Z=-3.91		<.001
Housemates are family or partner, % (n)	4	(6)	50	(12) ***	χ^2=41.79	1	<.001
Number of weekly contacts with housemates, mean (sd)	11.3	(8.6)	4.9	(8.0) ***	Z=-6.64		<.001

*p<.05, **p<.01, ***p<.001

Table 2 Social inclusion of service users of community housing programs

	Supported housing (n=154)		Supported independent living (n=101)		Test	df	p
Age, mean (sd)	43.8	(14.3)	44.5	(11.4)	t=-0.39	243.9	.694
Support from partner, family, and/or friends, % yes (n)	86	(132)	91	(92)	χ^2=1.65	1	.199
Weekly activities, total mean (sd)	9.8	(5.9)	13.5	(7.8) ***	Z=-4.10		<.001
• done alone, mean (sd)	5.3	(4.4)	7.2	(6.9)	Z=-1.77		.076
• done with others, mean (sd)	4.5	(3.7)	6.3	(5.2) **	Z=-2.28		.023
• sports, mean (sd)[1]	0.3	(0.6)	0.5	(1.0)	Z=-0.80		.421
Weekly service user visits, total mean (sd)	2.2	(2.1)	3.3	(3.1) **	Z=-2.98		.003
• received, mean (sd)	0.8	(1.3)	1.3	(1.8) *	Z=-2.54		.011
• made, mean (sd)	1.4	(1.7)	2.0	(2.3) *	Z=-2.35		.019
Vocational participation, % (n)							
• none	44	(67)	38	(38)	χ^2=0.87[2]	1	.351
• paid	8	(12)	8	(8)			
• voluntary	34	(53)	36	(37)			
• sheltered	14	(22)	18	(18)			
Hours per week spent on vocational activities (n=144), % (n)							
• 0-4 hrs	16	(13)	25	(15)	χ^2=6.67	5	.246
• 4-8 hrs	36	(30)	18	(11)			
• 8-16 hrs	17	(14)	21	(13)			
• 16-24 hrs	13	(11)	11	(7)			
• >24 hrs	18	(15)	25	(15)			
Unmet needs in areas concerning social inclusion, mean (sd)	0.7	(1.1)	1.0	(1.3) **	Z=-2.68		.007
• Social Contacts, % (n)	13	(20)	30	(30) **	χ^2=10.81	1	.001
• Intimate relationships, % (n)	17	(26)	24	(24)	χ^2=1.83	1	.176
• Safety to others, % (n)	1	(2)	2	(2)	χ^2=0.18	1	.668
• Taking care of children, % (n)	5	(7)	8	(8)	χ^2=1.26	1	.263
• Paid Employment, % (n)	7	(10)	11	(11)	χ^2=1.56	1	.212
• Daytime Activities, % (n)	10	(15)	16	(16)	χ^2=2.13	1	.145
Education/administration, % (n)	4	(6)	2	(2)	χ^2=0.73	1	.391
• Money, % (n)	7	(11)	9	(9)	χ^2=0.26	1	.608
• Welfare, % (n)	3	(4)	2	(2)	χ^2=0.10	1	.750
Satisfaction with daily life	6.9	(1.1)	6.5	(1.4) *	t=2.23	251	.027

*p<.05, **p<.01, ***p<.001

[1] 'sports' are included in the total number of activities (alone as well as with others). Sports include going to the gym, a sports club, participating in a walking or cycling group, etc.

[2] results reflect the comparison between being involved in vocational participation and not being involved in vocational participation.

hours per week or more. The majority (around 40% in both programs) does not participate in vocational activities.

The users of both housing programs report similar unmet needs in the areas of social inclusion, although the total number of unmet needs (in particular those reported in the area of Social contacts) is significantly higher for independently living people (Table 2). Almost one in three independently living service users report receiving no or insufficient support to meet their social needs, compared with slightly more than one in ten people in supported housing. Despite the relative high need for support in the area of Social contacts, the majority of service users do report support from a partner, family or friends. Overall, Social contacts and Relationships are the areas in which service users report having the most unmet needs, followed by Daytime activities and Paid employment. According to their diaries, service users rate their daily life with a mean score of 6.8 (sd 1.2) out of ten (ten=couldn't be better). Independently living service users are less satisfied with their daily life than people in supported housing.

To gain more insight into the differences in social inclusion between both housing programs, which seem to serve a similar group of users in respect to socio-demographic and clinical characteristics, we conducted the same multivariate analyses for service users who experience (very) severe problems in functioning (based on the division of HoNOS scores by Parabiaghi et al (2005). However, the results remain unaltered.

Discussion

In this explorative study, social inclusion is associated with the type of community housing program, i.e. supported housing and supported independent living. We found independently living service users to be more likely to be socially included, in terms of activities and visits, than people living in supported community housing programs. This is consistent with previous findings (Kallert, Leisse & Winiecki, 2007). However, this does seem to be at the expense of satisfaction with daily life and unmet needs. Also, being more independent in one's living situation and more (socially) active, does not seem to be associated with higher levels of participation in more competitive activities, such as paid employment. In both housing programs, only eight percent of service users have a regular paid job and roughly 40% of service users are not in any

way employed. Although these numbers themselves might seem discouraging, in an international perspective the Dutch service users seem to represent a relatively high level of vocational participation (De Heer-Wunderink et al, 2011).
Yet, there are several possible, and perhaps also complementary, explanations for our findings. First, the focus of RIRC care, concerning service users' daily life, may still be too much concentrated on aspects related to housing and 'having something to do', instead of on supporting and promoting service users to participate in the regular job market. For example, of all people without any vocational participation (n=105), only 9% is in a Supported Employment trajectory. Second, the broader social and economic context is important. People in supported housing programs cannot dispose of their total income, because their care is funded by the Exceptional Medical Expenses Act (Dutch acronym: AWBZ), for which they pay a statutory contribution. This income dependent contribution (ranging from € 146 to € 2 097 in 2011) is taken from their welfare, benefits or salary. Under current rules, service users who are not married are left with a minimum of € 455 spending money per month. An increase in income will result in a higher statutory contribution. This could mean that someone starting in paid employment has to cope with the downsides of having a job, without the financial gain. Although this policy is understandable, it is not vocationally stimulating. For independently living service users, similar arrangements exist. The height of their statutory contribution is less defined compared to supported housing, because the level and nature of support individually vary to a larger extent. Factors that are at least taken into account are income, family composition, age and the costs of the received care. Third, the dependency on a small income is in itself a barrier for social inclusion, because undertaking social activities and participating in social events come with various small or large expenses.

Another important social issue is the fact that people with SMI are often not able to follow and graduate from (post) secondary and tertiary education. Not having the right papers to gain access to paid employment creates an extra setback for these already vulnerable people. An intervention such as Supported Education (Murphy, Mullen & Spagnolo, 2005; Mombray, Korevaar & Bellamy, 2002; Mombray, 2000), which gives people with SMI the opportunity to study at a normal school with supports, may prove to be an important contributor in improving the educational tenure of service users, and there with their job perspective. Still, research into the effects of these programs in improving service user outcomes is largely missing. This should be addressed in future studies.

Finally, the multivariate analyses concerning social inclusion for the subset of service users who experience (very) severe problems in functioning – based on the division of HoNOS scores by Parabiaghi et al (2005) – rendered the same results as for the total sample. This is somewhat remarkable; one could argue that for this particular service user group, supported housing is probably better able to enhance social inclusion, bearing in mind the higher levels of staff supervision and professional support. Given the preference of service users to be as independent as possible and their need to be socially included, the decision to allocate people to these residential programs should therefore be very carefully considered.

Our study has some strengths. First of all, we used a large, representative sample of people residing in psychiatric community housing programs in the Netherlands and were able compare people in residential facilities with independently living people with SMI. Additionally, service users were involved in developing the diary to register their time use and social inclusion. Our main limitation lies in the cross sectional design of this study. We did not conduct a follow-up to establish if in time people are better off in one program or the other. Also, the service users were not randomly assigned to either program. We did ascertain that both service user groups are quite similar. Regarding the diary, we do not have information on how and under what circumstances each service user filled out the diary during the week.

Conclusions

Supported independent living programs compared to supported community housing programs seem to have a positive influence on the level of social inclusion, in terms of being active and receiving and making visits. Apart from this finding, we feel that the future challenge for mental health services, policy makers, professionals, service users and advocates, lies in improving the level of vocational participation of service users in both programs. Additional resources, such as Supported Education and Supported Employment programs, need to be made more readily available to people with SMI to improve their chances of social inclusion.

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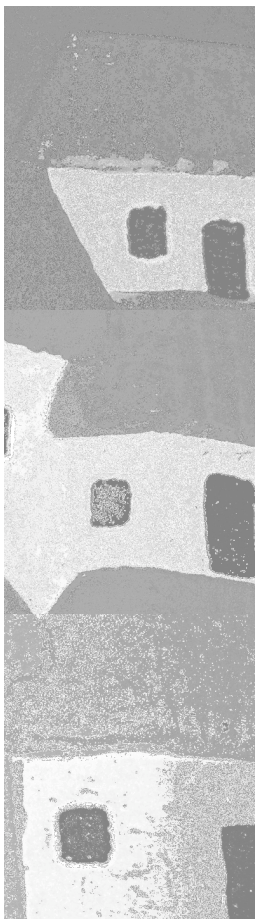

Treatment plans in Psychiatric Community Housing Programs: do they reflect Rehabilitation Principles?

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Psychiatric Rehabilitation Journal**:** accepted

Abstract

Objective

Determine the extent to which treatment plans of service users of community housing programs measure up to rehabilitation principles, according to the Choose-Get-Keep model of psychiatric rehabilitation. The study evaluates whether these plans correspond with service user- and key worker- perspectives on unmet needs for care.

Methods

A representative sample of key workers and service users of 16 Dutch Regional Institutes for Residential Care (RIRCs) participated in a cross-sectional survey. Socio-demographic and clinical data and an assessment of needs for care of 240 service users were collected. In addition, we received an anonymous copy of each participant's most recent written treatment plan. First, we developed a method to measure adherence to rehabilitation principles of written treatment plans, based on the Choose-Get-Keep model of psychiatric rehabilitation. Next, treatment plans were screened on the degree of adherence, expressed in a score from 0 to 10 for overall quality, and correlated with needs for care.

Results

RIRCs mostly seem to succeed in sufficiently integrating rehabilitation principles in their treatment plans. Adherence to rehabilitation principles was neither associated with the service user- nor with the key worker-perspective on needs for care.

Conclusions and Implications for practice

Rehabilitation principles are rather well documented in the majority of written treatment plans, although apparently without substantial consequences for needs for care among the service users. Further research is needed to validate our method and to investigate not only the adherence to rehabilitation principles in written treatment plans, but also in the actual care provision itself.

Introduction

In both the US and Western Europe, rehabilitation and recovery have increasingly become key principles in the care for people with severe mental illnesses (SMI) (Shepherd, 1984; Anthony, 1991; Anthony, Cohen, Farkas et al, 2002; Drake, Green, Mueser et al, 2003; Turton, Wright, White et al, 2010). Accordingly, mental health care services are gradually more oriented towards the development of the possibilities and strengths of an individual to lead a life like any other citizen, rather than focusing on psychiatric impairments. According to Anthony (1991), recovery denotes the individual, personal process that people with SMI experience while rehabilitation is what services do to facilitate recovery.

Research into the effectiveness of rehabilitation approaches has mainly focused on competitive employment. These studies revealed improvement on vocational as well as non-vocational outcomes for people with SMI (e.g., Burns et al, 2009; Campbell, Bond & Drake, 2009). Evidence on rehabilitation-based housing programs improving outcome of their service users is limited. Studies have shown that compared to hospital care, community care in general results in better service user quality of life and housing satisfaction (Shepherd, Muijen, Dean et al, 1996; Newman, 2001; Fakhoury, Murray, Shepherd et al, 2002). We found only one study specifically reporting about an illness management and recovery program in supported housing, revealing improved disease management and better functioning for service users in the program compared to a waitlist control group (Levitt, Mueser & DeGenova, 2009).

Also, across psychiatric settings information about the extent to which rehabilitation principles are actually adhered to is missing (Anthony, Cohen & Farkas, 1982). The Choose-Get-Keep model of psychiatric rehabilitation (Anthony et al, 2002), developed by the Center for Psychiatric Rehabilitation in Boston, provides rehabilitation program standards and includes guidelines for documenting rehabilitation goals. This offers the opportunity to use these guidelines to screen treatment plans on their adherence to rehabilitation principles. Regarding record keeping, Anthony et al (2002) state that 'the rehabilitation plan indentifies who is responsible for doing what, by when, for how long and where', with a specific focus on the process of a service user to 'Choose-Get-Keep a rehabilitation goal'.

Besides measuring adherence to rehabilitation principles of treatment plans, it is also worthwhile to associate the written treatment plan with the actual care practice. An

outcome measure such as service users' unmet needs, i.e., a need for care which is not (sufficiently) met, may provide some insight in the way daily care practice addresses rehabilitation goals.

In the present study, we introduce a method to measure the implementation of rehabilitation principles in community mental health services. We have screened the treatment plans of residents and independently living service users as to the fulfillment of a number of rehabilitation quality criteria, according to the Choose-Get-Keep model of psychiatric rehabilitation (further referred to as the Choose-Get-Keep model). The first aim is to determine the extent to which treatment plans measure up to rehabilitation principles. The second, to explore whether adherence of treatment plans to rehabilitation principles is related to the service user- and key worker-perspective on unmet needs for care.

Methods

Setting

In the Netherlands, 21 Regional Institutes for Residential Care (RIRC, Dutch acronym RIBW) provide residential care and support for independent living in the community. They have explicitly distinguished themselves from hospital-based long-stay facilities, since their focus of care is rehabilitation-oriented and mainly concerned with service users' daily living and participation in society. In January 2006, the RIRCs provided residential community care to 5 548 people (i.e., a mean of 0.6 per 1 000 of the total population of their catchment area), which is roughly half of the total number of beds in supported community accommodation, including those of the mental hospitals (Van Hoof, Knispel, Van Wijngaarden et al, 2009). Additionally, the RIRCs provided care to 6 797 people living on their own (i.e., a mean of 0.7 per 1000), which is also roughly half of the total number of people who need this kind of support (Dutch Mental Health Care Report, 2009).

All 21 RIRCs took part in the UTOPIA study (UTilization and Outcome of Patients In the Alliance of Dutch regional institutes for residential care), of which 16 participated in a cross-sectional survey including 121 randomly selected key workers (De Heer-Wunderink, Visser, Caro-Nienhuis et al, 2009). These key workers initially approached 1456 service users of which 818 (56%) gave written informed consent. Data were collected from September 2007 until July 2008. A representative sample of 240

service users and 76 key workers was selected for analysis of treatment plans. Service users who fully declined participation (non-participants) and participants who were not selected for analysis of treatment plans did not differ from our sample on socio-demographic and clinical characteristics. The medical ethics committee of the University Medical Center of Groningen (UMCG) considered formal approval for the UTOPIA study unnecessary.

Instruments

Service users completed a questionnaire, including socio-demographic data. The service users' key worker provided clinical data and an anonymous copy of the current treatment plan. Both service users and key workers reported their view on unmet needs for care through the Camberwell Assessment of Need Short Appraisal Scale (CANSAS; Phelan et al, 1995). This instrument rates needs for care for 22 items on a three point scale: 0 = no need, 1 = a met need (a problem which is (at least largely) solved by an intervention) and 2 = an unmet need (a problem is not solved, either because there is no intervention or the applied intervention is insufficient). The items include needs for food, looking after the home, daytime activities, psychical health, mental health, sexuality, relationships, transport, money, benefits, etc. Key workers were trained by the researches to use the CANSAS. Service users reported their needs for care on all CANSAS items during an interview with a member of the research team. Service users were asked if they were satisfied with for example, their daytime activities or if they had any wishes in this area. If they were satisfied or did not have any wishes, and also did not receive (professional) support in this area, the item of Daytime Activities was rated with 0 points (no need). If they did receive (professional) support, e.g., being in a vocational participation program, this item was rated with 1 point (met need). If they were not satisfied or did have a wish concerning activities, but reported to experience enough support to solve this issue, e.g., assistance in finding vocational participation, this item was also rated as a met need. If service users were not satisfied with their activities or had wishes, and did not receive (sufficient) support to solve this, this item was rated with 2 points, an unmet need.

Sample

The representative sample of 240 service users consists of 151 residents and (63%) and 89 independently living people (37%). For the total sample, the mean age is 44.5 years (sd 13.4), 54% is male, 72% has never been married, 45% are diagnosed with schizophrenia, and 25% with mood and/or anxiety disorders. Substance use disorders

are documented in 27%, and 38% of service users are diagnosed with an axis II disorder. More than half (53%) have received RIRC care for less than four years.

To guarantee familiarity with the organization and methods of support (trained in rehabilitation skills), only key workers employed for at least 24 hours per week during more than a year were selected. All were involved in day-to-day care.

Measuring adherence to rehabilitation criteria

In addition to information from the literature (Anthony et al, 1982; Anthony et al, 2002; Farkas, Gagne & Anthony, 2005), a team of three renowned Dutch rehabilitation experts were involved in deciding upon 10 key rehabilitation supporting criteria for treatment in community housing. These criteria were established by consensus and used in the screening of treatment plans in two steps. In step one, five criteria supporting rehabilitation (yes/no) applied to the total treatment plan - the so-called 'plan level' -:
1) Are rehabilitation goals formulated? Does the plan include goals that are skill oriented and behaviorally defined (Anthony et al, 2002)? A goal that is skill oriented could be formulated as: 'because I want to live independently, I want to learn how to prepare my own meals'. This goal is also behaviorally defined if it holds a description of the required conduct to achieve this goal. For example, 'in order to learn to prepare my own meals, I will do the groceries and my key worker will help me to prepare the meal, which I aim to do independently after two months.' A goal that is neither skill oriented nor behaviorally defined is: 'I want cook my own meals every day.' Such a description does not involve the skills and effort that are needed to fulfill this goal and does not do justice to the recovery process of the service user.
2) Is space reserved for written service user consent? The Recovery Values of 'person involvement' and 'self determination' entail that service users are at least involved in setting up and approving their treatment plan.
3) Is an evaluation date planned? A rehabilitation-oriented treatment plan design should include 'process and outcome measures related directly to the program's mission (growth potential)' (Farkas et al, 2005), to monitor the recovery process and create a feedback moment.
4) Is the plan written in the first person, reflecting a service user-centered approach (Anthony et al, 2002)? In order to enable recovery, treatment plans should be focused on the individual whishes of the service user (reflecting 'person orientation' and – 'involvement' and 'self determination'). These whishes can then be translated into

rehabilitation goals that are not decided upon by the health care professional but by the service users themselves, or in a reciprocal service user-key worker relationship.
5) Are emergency agreements available in case of a crisis? When people in general try to maximize their growth potential, stress can be a negative influence on this process. People with SMI are more vulnerable for these negative effects, which can cause relapse. When this happens, a safety net or support system is essential to minimize the negative consequences.
The fulfillment of each criterion is awarded one 'rehabilitation point', with a maximum score of five for the 'plan' level. Two researchers (EV& ADC-N) and a teacher of Rehabilitation at a University of Applied Sciences assessed and decided upon the fulfillment of these criteria by consensus.

In step two, on the so-called 'goal level', treatment goals as reported in the plan are evaluated. First, each goal is either assigned to one of six goal areas which are considered essential for rehabilitation: Housing, Work & Occupational Activities, Education, Recreation, Social Contacts, and Meaning in Life, or to one of three goal areas considered supportive of rehabilitation: Self-care, Mental Health and Physical Health. In case of more than one goal being reported for a specific area e.g., two goals on Housing, both are taken into account and averaged. Second, each goal area is evaluated according to the following five rehabilitation criteria, which are derived from the Choose-Get-Keep Program Model (Anthony et al, 2002):
1) Can we identify the rehabilitation phase of a goal? That is, is the goal aimed at choosing the recovery area to work on (Choose), or at stabilization of the current situation (Keep) or at improvement of the situation (Get)? An example of a 'Choose goal' is 'I feel able to expand my activities, but I am not sure if I want to do voluntary work or if I want to enroll in a computer class'. A 'Keep goal' can be described as 'to be able to stay in school and follow classes, I need to learn how to get to bed in time as well as get up in time'. A description such as 'to improve my social contacts, I will go to the day center twice a week and participate in activities and conversations that are going on' is a 'Get goal'.
2) Is there a time stipulated for evaluation of goal attainment, the questions *by when* and for *how long*? This provides evidence that the rehabilitation assessment includes an environmentally specific goal with projected timelines assigned to it (Anthony et al, 2002).
3) Which parties are involved (e.g., family, employment specialist, psychiatrist, etc.), the question *who*? Resource strengths and deficits should be listed and defined in the overall assessment (Anthony et al, 2002).

4) Is there a clear division of tasks among the parties involved, the question *what* needs to be done? The resources listed should be comprehensive, including supportive activities (Anthony et al, 2002).
5) Is the role of the service users' key worker clearly defined? This criterion was added to specifically evaluate the role of the involved community health care professional -i.e., the RIRC's key worker- in the recovery process of service users.
Again, each criterion is awarded one point with a maximum of five for the 'goal level'. Consensus assessment by the two researchers (EV & AC-N) and the teacher of Rehabilitation at a University of Applied Sciences decided upon the fulfillment of these criteria in the various goal areas. For the goal level, this results in a mean score per rehabilitation criterion. For example, when a treatment plan contains two goal areas, e.g., Housing and Mental Health, and only one fulfils the first criterion of an identifiable rehabilitation phase, a score of 0.50 is awarded to this criterion.

The score for the 'plan level' and 'goal level' add up to an adherence score of a treatment plan as a whole, with a maximum of ten points if all criteria on both levels are met. We used the following rule of thumb for a classification of the quality of the rehabilitation approach of a plan:
1) A score of three or less: no adherence to rehabilitation principles;
2) A score from four to six: insufficient adherence;
3) A score of seven or eight: sufficient adherence;
4) A score higher than eight: substantial adherence to rehabilitation principles.

This rule of thumb is based on the Dutch grading system, used throughout the Dutch education system. On a scale from one (=very bad) to ten (=excellent), six is the 'minimum pass'. For a plan to show sufficient adherence to rehabilitation principles we consider a 'minimum pass' to be inadequate, it at least needs to fulfill seven out of ten criteria. We want to emphasize that we are screening the paperwork (the product) and not the actual people work (the process).

Unmet needs for care

To associate reported goal areas in a treatment plan with the service user- and key worker-perspective on unmet needs for care according to the CANSAS, the needs were distributed to these goal areas. Because of small numbers of goals in the three areas of Work & Occupational Activities, Education and Recreation, they were grouped into one goal area, named 'Daytime activities', and correspondingly, needs relating to Daytime Activities were assigned to this goal area. Needs relating to Safety to Others,

Company, Intimate Relationships, Sexual Expression, and Childcare were linked to the goal area of Social Contacts; needs relating to Accommodation to the goal area of Housing; the CANSAS item of Meaning in Life (developed by Delespaul, Bak, Gunther et al (2004) and added to the original items) was subsumed under the goal area of Meaning in Life. Remaining needs were categorized in three goal areas which are considered to be supportive of rehabilitation: needs relating to Food, Looking After the Home, Self-care, Basic Education, Telephone, Transport, Money and Benefits in the goal area of Self-care; needs relating to Information about Treatment, Psychological Distress, Safety to Self, Alcohol and Drugs in the area of Mental Health; and needs relating to Physical Health in the goal area of Physical Health. The correspondence of the treatment plan with unmet needs was calculated as the percentage of unmet needs that were actually reported in the linked goal area.

Data analysis

SPSS (version 16) was used to perform logistic regression analyses to study associations between socio-demographic and clinical characteristics and the quality of the 'plan level'. The generalized linear model (GLM) was applied to analyze these interrelations on the 'goal level'. Non-parametric correlation tests were performed to associate the total mean quality of the treatment plan with the service user- and key worker-perspective on (unmet) needs for care.

Results

Socio-demographic and clinical characteristics

Residents differ from independently living people with SMI in the following characteristics: residents are more likely to be diagnosed with schizophrenia (χ^2=8.60, df=1, p<0.01), and less likely to be diagnosed with mood and anxiety disorders (χ^2=12.82, df=1, p<0.001). Socio-demographic and clinical characteristics, including residential status, were not associated with the quality of the 'plan level', the 'goal level' or the total quality of the treatment plan.

Adherence of treatment plans to rehabilitation criteria

Plan level

Rehabilitation goals are present in almost all treatment plans (Table 1 on the next page), whereas the other four quality criteria are so less often. In particular,

formulating a plan in the first person, reflecting a service user-centered approach, only occurs in half of the treatment plans. Emergency agreements appear to be scarcely ever integrated in the plan, which is remarkable, considering that service users cope with severe psychiatric impairments. The mean 'plan level' score is 3.1 (sd 0.9) out of a maximum of 5 points. Of all service users (n=240), 22% (n=55) have a 'plan level' score of 2 or lower and only 5% (n=11) reached the maximum score of 5.

Goal level

All goal areas have a mean number of goals between 1.0 and 1.4, with the exception of the area of Self-care (mean number of 2.3 (sd 1.4) goals). When a goal is reported, the majority of rehabilitation criteria appear to be met (Table 1).

Table 1 Quality criteria of the treatment plan (n=240)

		%	n
Plan level			
1	Rehabilitation goal formulated	97	(233)
2	Signing space for service user consent	78	(187)
3	Date planned for treatment plan evaluation	76	(182)
4	Plan formulated in the first person	50	(119)
5	Emergency agreements	15	(35)
Goal level			
6	Rehabilitation phase identified	97	(233)
7	Period planned to achieve goal	97	(233)
8	Parties involved in goal achievement	97	(233)
9	Clearly defined tasks of involved parties in goal attainment	94	(226)
10	Role of care-coordinator in goal attainment	90	(215)

The mean 'goal level' score is 4.0 (sd 1.1) out of a maximum of 5.0. Of all service users (n=240), 6% (n=14) have a 'goal level' score of 2.0 or lower (including those with no rehabilitation goals), 33% (n=78) received the maximum score of 5.0.

Quality of the treatment plan as a whole

The mean quality of the treatment plan as a whole –including plan level and goal level- is 6.8 (sd 1.9, median 7.3) out of a maximum of 10.0. According to our four-level classification of quality, 66% (n=158) of treatment plans show at least a sufficient degree of adherence to rehabilitation principles (Table 2 on the next page).

The overall mean quality of the treatment plan (i.e., 6.8 out of 10.0) was neither significantly associated with the service user- nor key worker-perspective on total number of unmet needs for care and total needs for care.

Table 2 Overall quality of treatment plans according to rehabilitation criteria (n=240)

			%	n
Quality score				
1	(0-3)	No adherence	4	(10)
2	(4-6)	Insufficient adherence	30	(72)
3	(7-8)	Sufficient adherence	52	(125)
4	(9-10)	Substantial/full adherence	14	(33)

Correspondence of treatment plan goals with unmet needs

The most prevalent goals in treatment plans, in decreasing order, are in the goal areas of Self-care, Daytime Activities, Mental Health and Social Contacts (Table 3 on the next page). The high prevalence of in particular the goal area of Self-care, and also the goal area of Mental Health suggests that the main needs for care of service users of Dutch RIRCs mostly lie in basic necessities of life, at least according to their service providers.

Service users themselves report the most needs for care in the areas of Mental health (42%, n=101), Social contacts (30%, n=71), and Physical health (28%, n=67) (Table 3 column 2). Although at least half of the unmet needs in the area of Mental health and Social contacts are reflected in treatment plans, this is only true for one fifth of the unmet needs in the area of Physical health (21%, n=14; Table 3). The unmet needs in the area of Self-care are best represented in treatment plans, although a relatively small percentage of service users (12%) report an unmet need in this area.

Key workers may have another perspective on the unmet needs of service users. They report the highest number of unmet needs in the areas of Social contacts (33%, n=78), Mental Health (29%, n=69), Self-care (20%, n=48) and Meaning in life (20%, n=48). Although the Rehabilitation goal areas of Social contacts and Meaning in life are relatively frequently rated as an unmet need, their correspondence with actual goals in treatment plans, especially in the area of Meaning in life, is low.

Table 3 Correspondence between treatment plan goals and unmet needs according to service users as well as key workers (n=240)

			Service users		Key workers	
Goal area	Goal area present in treatment plan		Unmet need corresponding to goal area		Unmet need corresponding to goal area	
	%	**(n)**	**%**	**(proportion)**	**%**	**(proportion)**
Rehabilitation						
Daytime activities	59	(142)	55	(16/29)	63	(24/38)
Social contacts	51	(123)	52	(37/71)	62	(48/78)
Housing	43	(104)	67	(2/3)	50	(1/2)
Meaning in life	5	(12)	0	(0/29)	4	(2/48)
Supporting rehabilitation						
Self-care	74	(177)	69	(20/29)	81	(39/48)
Mental health	53	(128)	58	(59/101)	57	(39/69)
Physical health	20	(47)	21	(14/67)	32	(11/34)

All treatment plans were drawn up in the twelve months prior to the needs assessment, and 66% (n=158) even in the six months before. The mean length of this time period was not significantly associated with whether or not a treatment goal corresponded with the service user- or key worker-perspective on unmet needs or with the quality of the treatment plan.

Conclusion

Two thirds of treatment plans in community housing programs in The Netherlands show at least a sufficient degree of adherence to rehabilitation principles. However, this appears to be without substantial consequences for needs for care among the service users. It seems there are still discrepancies between what service users report to be their unmet needs, and what is incorporated in treatment plan goals. For example, in the goal area of Mental health which shows the highest number of unmet needs reported by service users, only about 60% of the total number of unmet needs is reflected in a treatment plan goal. In the areas of Social contacts and Physical health, where service users also frequently report unmet needs, the correspondence with

treatment plan goals is even lower. The key worker perspective on unmet needs shows somewhat more correspondence to the content of treatment plans.
To our knowledge, this is the first large-scale study that attempts to measure adherence to rehabilitation principles in rehabilitation services in community mental health care. It could be considered as a first step to develop a kind of fidelity method of rehabilitation practice. The main limitation of our study is that we only considered treatment plans' adherence to rehabilitation principles, and not the actual care provision itself.

Although rehabilitation goals were present in almost all treatment plans, we found that one-third still leaves substantial room for improvement. For example, it seems that service users' involvement in treatment planning, reflected in the first person-formulation of goals and written service user consent, is less prominent than one would expect in rehabilitation-based housing programs. Especially, since the key workers are trained to apply rehabilitation skills in treatment and record keeping. However, one should also bear in mind that even if both first person-formulation and written service user consent are present in a treatment plan, this does not necessarily indicate active service user involvement.

In addition, our expectation that a better adherence to rehabilitation principles would coincide with a higher level of coverage of unmet needs in treatment plan goals could not be confirmed. There might be a number of reasons for not finding the expected association. First, there possibly is a discrepancy between the treatment agreed on on paper (the product) and the actual care practice (the process). Setting up a treatment plan according to rehabilitation principles is one thing, involving a service user in treatment planning and the practice of achieving rehabilitation goals is another. There are many factors that can influence the way goals are realized and the timeframe that is needed to do so, e.g., the mental state of the service user, his/her physical surroundings (neighborhood, city), the social support system (family, friends), the involved (mental) health professionals, etc. Besides treatment plan evaluation, which is carried out by the involved key worker and service user at least once a year, routine outcome monitoring of the RIRCs' care provision is currently lacking, making it impossible to monitor individual service users and their treatment over time in a standardized manner.
Second, (un)met needs are not necessarily equal to rehabilitation goals. One could have a rehabilitation goal in the area of work, e.g., expanding working hours, while not having an unmet need in this area because the support received to achieve this goal is adequate. However, when someone reports an unmet need in the area of work, this

should always be addressed in the treatment plan, because an unmet need denotes either a lack of support or inadequate support to fulfill this need. Third, in all cases the treatment plan was drawn up prior to the needs assessment required for this study (ranging from 1 to 12 months). This implies an uncontrollable time lag between the treatment plan and the needs assessment, during which needs could come and go (Wiersma, Van den Brink, Wolters et al, 2009). Since overall correspondence of the treatment plans with unmet needs was not associated with this time lag, this suggests that treatment goals in community housing programs are mostly long term and will therefore reflect more stable unmet needs. Finally, the criteria used in the present study could be questioned. However, we believe they offer a reasonable reflection of key elements of rehabilitation, such as service user consent and service user involvement in decision-making. Nevertheless, their validity should be further explored.

Although an extensive body of research on needs is available (e.g., Lasalvia, Ruggeri, Mazzi, et al, 2000; Wennström & Wiesel, 2006), the relationship between (unmet) needs and treatment plans with rehabilitation goals has to our knowledge never before been studied.

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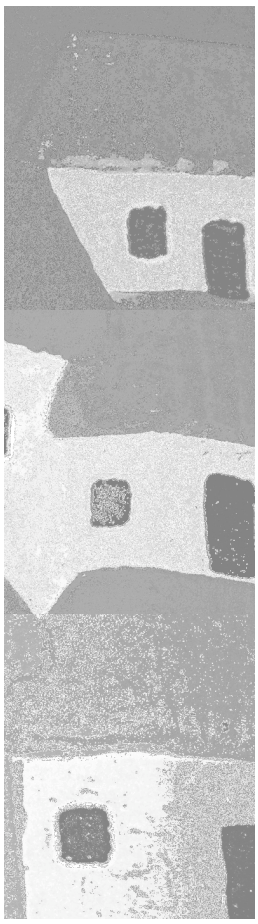

The Role of Helping Alliance in Psychiatric Community Housing Programs: a large-scale cross-sectional survey

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Submitted

Abstract

Objectives

Helping alliance between practitioners and service users is a crucial part of mental health care provision. This paper investigates the strength of helping alliance, and its interrelationship with levels of functioning and (agreement on) need for care of service users and key workers in supported housing and supported independent living programmes.

Methods

Data was collected from a random sample of 105 key workers (i.e., nurses, social workers) and 584 service users. Service users completed a questionnaire including socio-demographic information, and were interviewed to assess helping alliance and care needs. Key workers provided data on helping alliance, service user functioning, and their perspective on care needs. We performed univariate and multivariate analyses of the associations between helping alliance and service user outcomes.

Results

In both housing programmes, helping alliance is negatively associated with unmet care needs. In supported housing, helping alliance is also associated with general agreement on care needs between service users and key workers.

Conclusions

Our findings suggest that investing in the therapeutic relationship is a means to reduce service users' unmet needs. In supported housing, it seems that improving the therapeutic relationship also contributes to the consensus between service users and key workers concerning the direction of support.

Introduction

In mental health care, the quality of the therapeutic relationship and especially the *helping* (or *working* or *therapeutic) alliance* between practitioner and service user is considered essential for improving treatment outcomes (McGuire, McCabe & Priebe, 2001; Hörberg, Brunt & Axelsson, 2004; Priebe & McCabe, 2006; Shattell, Starr & Thomas et al, 2007). These findings are consistent across mental health care settings. Extensive research has been done in the field of psychotherapy (Catty, 2004; Horvath & Symonds, 1991; Martin et al, 2000), but there is also evidence of a positive effect in child and adolescent therapy (Shirk & Karver, 2003) and community case management (Fakhoury, White & Priebe, 2007; Tattan & Tarrier, 2000; Calsyn, Klinkenberg, Morse et al, 2006; Howgego, Yellowlees, Owen et al, 2003; De Leeuw, Van Meijel, Grypdonck et al, 2011). For service users, the helping alliance is one of the most important aspects of 'good care' (Johansson & Eklund, 2003).

Although previous studies have established that the helping alliance contributes to better treatment outcomes in community psychiatry, these studies have mainly focussed on (assertive) community case management. Research into service user outcomes, including helping alliance, in psychiatric community housing programmes is largely missing (Fakhoury, Murray, Shepherd et al, 2002). Community housing programmes are the preferred alternative for people with severe mental illness (SMI) who would otherwise be allocated a long ward stay or placed in a housing programme on hospital grounds. Browne (2008) argues that housing is a critical intervention influencing long-term outcomes and recovery for its service users.

In the Netherlands, we differentiate between supported housing programmes and supported independent living programmes. Supported independent living programmes provide care for people with SMI who are able to live in their own home. In this respect, these programmes might to some extent resemble community case management programmes. However, a clear distinction lies in the focus of support. In community case management, the support provided revolves primarily around the treatment of, and coping with, the mental illness. In supported independent living programmes, the support first and foremost aims at the Psychiatric Rehabilitation and Recovery of service users (Anthony, Cohen, Farkas et al, 2002). It focusses on the service users' own preferences and priorities for support in the daily struggles they experience. Supported housing is similar to supported independent living programmes in this respect, although its service users do not live in their own home,

but in a residential facility with other service users and with permanent staff supervision. This difference between community case management and housing programmes makes it seem likely that the helping alliance is even more important in the latter. As service users determine the direction of their support, key workers need to be helpful, yet modest. This calls for mutual respect and confidence, and the ability to engage in shared decision making (Adams & Drake, 2006), which are in themselves important aspects of the helping alliance (Hougaard, 1994). Furthermore, it is interesting to investigate the helping alliance/service user outcome relationship between housing programmes, in order to gain insight into the influence of care intensity on the therapeutic relationship.

In the present study, we aim to explore the strength of the helping alliance in supported housing and supported independent living programmes. We investigate whether the role of the helping alliance differs between these programmes in its relationship with service user outcomes.

Materials and methods

Setting

This study is part of the UTOPIA-study (UTilization and Outcome Of Patients In the Alliance of residential care facilities), a large scale national survey in the Netherlands among key workers and service users of community housing programmes, who either live in supported housing facilities or receive support for independent living in their own home (De Heer-Wunderink, Caro-Nienhuis, Sytema et al, 2008, De Heer-Wunderink, Visser, Caro-Nienhuis et al, 2011). Twenty two Dutch Regional Institutes for Residential Care (RIRC, Dutch acronym RIBW) provide supported housing and supported independent living programmes in the community. The Exceptional Medical Expenses Act funds their care provision. Supported housing is allocated when an applicant has a psychiatric impairment, and needs a protective living environment and/or permanent supervision. Supported independent living is allocated when the applicant suffers from moderate or severe impairments in the area of social independence, mental functioning or cognitive skills or has moderate or severe behavioural problems, without the need for a protective living environment and permanent supervision.

RIRCs have explicitly distinguished themselves from hospital-based long stay facilities in their focus of care, which is daily living and participation in society rather than the

treatment of psychiatric symptoms (De Heer-Wunderink et al, 2011). Residential housing facilities consist mostly of one-family homes. Additionally, there is an increasing number of one and two person apartments to meet the growing need for privacy expressed by new long stay service users (Fakhoury, Priebe & Quraishi, 2005; Tsai et al, 2009). To encourage occupational participation, day centres, supported employment projects, and job coaching are also part of the RIRCs' care provision. All service users, residents as well as those living independently, receive support from a key worker, who is skilled in applying Rehabilitation (Anthony, 2002).

Sixteen RIRCs participated in this study; the other six were unable to do so for various reasons (e.g. reorganisation, lack of permission to draw a random sample of key workers etc). We asked each RIRC to make a list of all key workers who fulfilled the following criteria:

- Involved in the day-to-day care for service users;
- Employed for at least 24 hours per week;
- Employed by the RIRC for more than one year, in order to guarantee familiarity with the organisation and methods of support (rehabilitation).

We randomly selected 192 key workers, who have various professional backgrounds such as nursing and social work, of which 119 (about 10% of the total number of key workers working in those RIRCs and 62% of the random sample) participated. These key workers initially approached 1432 service users of which 818 (57%) gave written informed consent. Only participants with complete data sets were selected for this study, which resulted in a total number of 584 service users (71%). Participating and non-participating service users did not differ on gender, age, diagnosis, substance use or personality disorder. The study was submitted for approval to the medical ethics committee of the University Medical Health Centre in Groningen, which stated that formal approval was not required due to the non-invasive study design.

Materials

Helping alliance was assessed using the Helping Alliance Scale (HAS; Priebe & Gruyters, 1993). This was chosen because it is brief and easy for service users to understand. It also has acceptable internal consistency across different patient groups (McCabe & Priebe, 2003), which is important because service users of housing programmes are heterogeneous in this respect. It has a service user version (HAS-Patient or HAS-P) consisting of five items, which are scored from 0 (not at all) to 10 (entirely) asking: a) Is the treatment you are currently receiving right for you? b) Do

you feel understood by your key worker? c) Do you feel criticised by your key worker? d) Is your key worker committed to and actively involved in your treatment? e) Do you have trust in your key worker and his/her professional competence? The internal consistency of this scale in our dataset was adequate (Cronbach's alpha = 0.81).

The key worker version (HAS-Staff or HAS-S) consists of the following five items, which are also scored on a scale from 0 (not at all) to 10 (entirely): a) Do you get along with the service user? b) Do you understand the service user and his/her views? c) Do you look forward to meeting the service user? d) Do you feel actively involved in the service user's treatment? e) Do you feel you can help the service user and treat him/her effectively? These items showed good internal consistency in our dataset (Cronbach's alpha = 0.87).

Service users completed a questionnaire, including socio-demographic data and were interviewed to assess helping alliance and their care needs. The Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) (Phelan, Slade, Thornicroft et al, 1995) was used to assess service user as well as key worker view on care needs. Needs are rated for 22 items on a three point scale: 0 = no need, 1 = a met need (a problem which is (at least largely) solved by an intervention) and 2 = an unmet need (a problem is not solved, either because there is no intervention or the applied intervention is not sufficient). We also investigated agreement about needs for care in general, between service users and key workers. At face value, it seems likely that a better agreement on whether there is a(n) (un)met need for care in a certain area or not, contributes to the strength of the helping alliance. Agreement scores were calculated per CANSAS item by subtracting the key worker rating from the service user rating. If both parties rated the item equally, the item was assigned 1 agreement point, which represents full agreement. If the ratings differed by 1 point (e.g. for a service user rating of 1 (met need) and a key worker rating of 2 (unmet need) or 0 (no need)), 0.5 agreement points were assigned. A difference between ratings of 2 points (the difference between 'no need' and 'unmet need') received 0 agreement points. An overall mean CANSAS agreement score was calculated per service user. Key workers provided clinical data and an assessment of the service users' level of functioning on the Health of the Nation Outcome Scales (HoNOS; Wing, Beevor, Curtis et al, 1998). The HoNOS consists of 12 domains of functioning, which are rated on a scale between 0 (=no problem) to 4 (= (very) severe problem). The total mean HoNOS score is the mean sum of the scores in 12 domains. Key workers were trained to use this tool by the researchers (CH-W, AC-N and EV). A training day, which in general was attended by key workers from three RIRCs at the same time, consisted of instruction in the

morning, and filling out the HoNOS- and CANSAS-forms for all their service user participants in the afternoon. This procedure allowed them to provide feedback in the case of scoring problems.

Data analysis

Statistical analyses were conducted with SPSS 18.0.3. Univariate tests (χ^2, Mann Whitney U-test) were performed to compare service users in supported housing with independently living service users. The Wilcoxon Signed Ranks test was performed to investigate differences between the helping alliance ratings of service users and key workers. Within the two housing programmes, nonparametric correlation coefficients (Kendall's tau_b) were calculated to associate the helping alliance ratings with service user outcomes regarding level of functioning, service user rated unmet needs, and general agreement between service users and key workers on needs for care. Multivariate analyses were performed, controlled for significant univariate associations of service user outcomes with socio-demographic, clinical and care characteristics, to associate the helping alliance ratings with service user outcomes in supported housing programmes as well as in supported independent living programmes. The significance level was set at $p<0.01$.

Results

Sample

An overview of socio-demographic and clinical characteristics and outcomes of service users of supported housing and supported independent living programmes is given in Table 1. Most service users are male, unmarried, and middle aged. More than half the residents were diagnosed with schizophrenia, compared to a third of independently living service users. This difference is statistically significant. Residents are also more likely to be coping with a substance use disorder (table 1). The two service user groups do not differ on personality disorder, length of stay, hospitalisation in the past year, or level of functioning (total mean HoNOS score). For helping alliance, we found a marginally significant trend for independently living service users to be more positive than residents ($p=0.027$; Table 1). Service users of both housing programmes rate alliance fairly highly (Table 1). These results also apply to key worker rated helping alliance. We did not establish a difference between housing programmes in the mean overall agreement between service users and key workers about needs for care.

Helping alliance as experienced by service users and key workers

Experience of helping alliance is reasonably strong for service users in both housing programmes (Table 1). We found a significant difference between service user and key worker helping alliance ratings in supported housing (Z=-3.864, p<0.001), as well as in the independent living programme (Z=-3.919, p<0.001). In general, service users are more positive about the therapeutic relationship than key workers.

Table 1 Socio-demographic and clinical characteristics and service user outcomes; residents and independently living service users compared

	Residents		**Independently living service users**		**Test**	**p**
	(n=363)		(n=221)			
Socio-demographic and clinical characteristics						
Age, mean (sd)	44	(14.0)	44	(12.3)	t=-0.76	.447
Male, % (n)	61	(220)	48	(107) *	χ^2=8.28	.004
Never married, % (n)	70	(255)	70	(155)	χ^2=0.00	.977
Schizophrenia (yes), % (n)	51	(186)	30	(66) *	χ2=2.55	<.001
Personality disorder, % (n)	34	(125)	41	(90)	χ2=2.34	.126
Substance use disorder, % (n)	32	(117)	21	(46) *	χ2=8.90	.003
Length of stay < 4 years, % (n)	49	(176)	59	(129)	χ2=5.58	.018
Hospitalization in the past year, % (n)	20	(71)	15	(33)	χ2=2.27	.132
Service user outcomes						
Helping Alliance						
• HAS service users, mean (sd)	7.5	(1.3)	7.8	(1.1)	Z=-2.21	.027
• HAS key workers, mean (sd)	7.2	(0.9)	7.5	(0.8) *	Z=-2.90	.004
HoNOS score, mean (sd)	11.7	(5.9)	11.5	(6.8)	Z=-0.73	.465
Needs for care, mean (sd)						
• Unmet needs service user	1.2	(1.5)	1.5	(1.8)	Z=-1.86	.063
• General agreement on needs for care	0.8	(0.1)	0.8	(0.1)	Z=-1.83	.067

* p<0.01

The role of helping alliance in service user functioning and needs for care in supported housing and supported independent living programmes

Supported Housing programmes

Unadjusted as well as adjusted service user rated helping alliance is significantly associated with service user rated unmet needs, but not with level of functioning (Table 2a on the next page). For service users (as well as key workers), helping

alliance increases when the total mean number of unmet needs decreases. In addition, the adjusted analyses showed a significant association between service user rated helping alliance and general agreement between service users and key workers on needs for care.

Table 2a Univariate and multivariate associations between helping alliance (HAS-P) and service user outcomes in Supported Housing Programmes

Supported Housing	**Level of functioning**		**Service user rated unmet needs**		**General agreement on needs for care between service users and key workers**	
Univariate analyses, Kendall's tau-b correlation						
Service user rated helping alliance (HAS-P)	-0.054		-0.148 **		0.085	
Multivariate analyses	**Beta**	**t**	**Beta**	**t**	**Beta**	**t**
Service user rated helping alliance (HAS-P)[1]	-0.120	-2.283	-0.233	-4.521**	0.179	3.449 *
Model, F(9-342)	R^2=0.07, F=2.91**		R^2=0.11, F=4.67**		R^2=0.10, F=4.28**	

* p<0.01, ** p<0.001

[1] Controlled for age, gender, never married, schizophrenia, RIRC care < 4 years, substance use disorder, personality disorder, admission to mental hospital

Table 2b Univariate and multivariate associations between helping alliance (HAS-P) and service user outcomes in Supported Independent Living Programmes

Supported Independent Living	**Level of functioning**		**Service user rated unmet needs**		**General agreement on needs for care between service users and key workers**	
Univariate analyses, Kendall's tau-b correlation						
Service user rated helping alliance (HAS-P)	-0.002		-0.144**		0.051	
Multivariate analyses	**Beta**	**t**	**Beta**	**t**	**Beta**	**t**
Service user rated helping alliance (HAS-P)[1]	-0.020	-0.320	-0.209	-3.108*	0.048	0.701
Model, F(9-342)	R^2=0.24, F=6.25**		R^2=0.13, F=3.47**		R^2=0.13, F=3,47**	

* p<0.01, ** p<0.001

[1] Controlled for age, gender, never married, schizophrenia, RIRC care < 4 years, substance use disorder, personality disorder, and admission to mental hospital

Supported Independent Living Programmes
In supported independent living programmes, unadjusted as well as adjusted service user rated helping alliance is associated with service user rated unmet needs (Table 2b on the previous page). In these housing programmes key worker rated helping alliance was not significantly associated with any of the service user outcomes.

Discussion

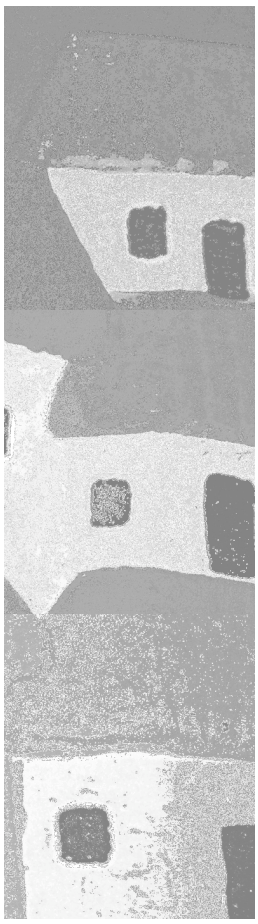
In supported housing and supported independent living programmes, an increase in service user experienced helping alliance is significantly associated with a decrease in service user rated unmet needs. A randomised controlled trial (RCT) by Junghan, Leese, Priebe et al (2007) on helping alliance in community mental health services also established this relationship. They conclude that a focus on service user rated unmet needs in interventions and assessment will maximise service user-rated therapeutic alliance. Our results specifically substantiate these findings for community housing programmes. In supported housing as opposed to supported independent living programmes, an increase in helping alliance is associated with more agreement between service users and key workers on needs for care. It is likely that frequency and intensity of therapeutic contact are important for this association. The higher dependency on care or support provided by others in supported housing programmes will increase the influence of this support on daily life. Consequently, there will be an increased need for the receiver and provider of support to agree on what needs to be done. This further underlines the importance of shared decision making in achieving treatment success. Nevertheless, helping alliance ratings of both service users groups are fairly high. This is consistent with previous findings (Tryon, Blackwell & Hammel, 2008).

Our study has several limitations. The cross-sectional design does not allow for causal explanations. To guarantee anonymity, we have little information on key worker characteristics, other than the criteria used to select key workers eligible for our random sample. This has restricted our ability to analyse key worker-alliance ratings, e.g. we could not determine the association of these ratings with key worker characteristics and the association between key worker characteristics and service user alliance ratings and outcomes. It would also be interesting to investigate the differences in the helping alliance between supported independent living programmes and community case management. At face value, it seems possible that helping

alliance is stronger in the first programmes because the service users themselves define the wishes and problems on which care is focussed, instead of the mental health professional.

An important strength of our study is the size and representativeness of the sample and therefore the ability to generalise the findings to the Dutch SMI population in community housing programmes. In this context, it may provide useful information for future research, as well as for daily care practice.

7



General discussion

Overview of the Study

The UTOPIA study, reported in this thesis, is the first large-scale cross-sectional survey into psychiatric community housing programmes in the Netherlands. All Dutch RIRCs (Regional Institutes for Residential Care, Dutch acronym: RIBW) participated in this research project, which investigates their care provision, their key workers' professional attitudes, and their service users' lives. We have gathered new information on a scarcely evaluated field of Dutch community care, and the results of the study can be generalized to other service user populations in these programmes. We investigated developments of RIRCs (e.g., the size and increase of the service user population, their organization and focus of care), the characteristics of supported housing and supported independent living programmes (e.g., the way service users live together, the way key workers are educated and trained) and the characteristics of their service users (e.g., socio-demographic and clinical characteristics, content of care, quality of life, levels of functioning, needs for care and degree of social inclusion). Furthermore, we evaluated Dutch RIRCs and their service users from an international perspective, investigating (dis)similarities with housing programmes in other countries.

From a European perspective we found Dutch service users of housing programmes to be quite similar to Italian and English service users in comparable programmes despite different deinstitutionalization processes in these countries. At face value one would expect community housing programmes in a country with relatively low thresholds to mental hospital access, such as the Netherlands, to provide care to a service-user population that is generally less disabled than similar programmes in countries where access to mental hospitals is much more difficult or even non-existent. The Italian and English service-user population do seem more similar to the former mental hospital long-stay population in that they are more likely to be diagnosed with schizophrenia. Our finding that Dutch RIRCs are better able to arrange service users' participation in vocational programmes could also reflect a more stable, less impaired service-user population. However, this can also indicate that the primary focus of RIRC care on social inclusion instead of on treating psychiatric symptoms has beneficial effects. Still, more detailed information on the functioning and the focus of care provision across countries is needed to substantiate our findings.

Also, in England and the Netherlands residents and independently living service users appear to have quite comparable socio-demographic and clinical characteristics. This

raises the question whether some of the current residents would be able to make the transition to a more independent living situation. This is a relevant issue, not only from the point of view of cost-effectiveness, but also from an ideological perspective. RIRCs use rehabilitation and recovery principles to shape their care and treatment plans. Social inclusion and service user autonomy are central to the rehabilitation concept. A transfer from residential care to an independent living situation would perfectly match the core goals of the RIRCs. The UTOPIA study provides clues on which residents may be eligible for such relocation based on their relatively minor problems in functioning. As mentioned earlier, we found Dutch RIRCs to be relatively successful in arranging vocational participation for their service users compared with English housing programmes. However, true social inclusion in the sense that RIRCs' service users have 'normal' friends, participate in social activities outside their peer group, follow education, have a regular job etc. is still far away. Even though independently living people with SMI have more social contacts and undertake more activities than those in residential care, of both service-user groups only one in ten is in paid employment.

In an investigation of the rehabilitation-content of RIRC treatment plans we found principles of rehabilitation to be sufficiently integrated in two-thirds of the plans. These principles include a service-user-centred approach, first-person language, a clear description of rehabilitation goals and the means and people involved in the achievement of goals, and consent of service users. Nevertheless, we could not establish a relationship between the treatment plans' level of adherence to rehabilitation principles and the level of agreement between treatment plans and service users' unmet needs. It seems that rehabilitation-oriented care does not imply care that is more in line with service users' needs.

In rehabilitation-oriented care the helping alliance between service users and key workers is commonly considered paramount, as much as shared decision-making is central to the helping alliance. Shared decision making involves an equal discussion between care consumers and professionals upon goals and the nature of support and eventually their mutual agreement. Within RIRCs, service users and key workers generally give a good rating to the helping alliance. In supported housing as well as supported independent living programmes we found a stronger helping alliance to be associated with less unmet needs for care. In supported housing, a stronger helping alliance was also associated with better general agreement between service users and key workers on needs for care.

Limitations

The choice of a cross-sectional design for the UTOPIA study enabled us to reach the entire RIRC sector and all of their service users. This was crucial to improve our insight into this area of community mental health care and its service users.

However, a disadvantage of the cross-sectional design is that it does not allow conclusions on the effectiveness of RIRC care or its constituents by comparing them with a control condition. What are needed are reliably and thoroughly designed (randomized) controlled trials ((R)CTs) into rehabilitation-oriented housing programmes (Michon & Van Weeghel, 2008). The results of the UTOPIA study can only indicate the direction of these trials. For example, on care allocation: are service users better off in supported housing or living independently with support, in terms of quality of life, quality of care, level of social inclusion, needs for care etc.? And what about the orientation of care: is rehabilitation-oriented RIRC care more effective in improving outcomes for service users in comparison with treatment-oriented community care? When setting up a (randomized) controlled trial in this field, one would have to deal with a number of challenges. These programmes are characterized by diverse staffing arrangements, a heterogeneous service-user population, unevenly motivated subjects and dependence on broader social environments (i.e., a viable household, a supportive neighbourhood, availability of jobs, presence of a social network, location in a city etc.). These 'real world conditions' complicate the strict use of protocols, equivalent experimental and control groups and neutral, comparable trial environments (Wolff, 2000; Wolff, 2001). However, this should not prevent us from setting up trials that meet these demands.

A second limitation of the current study is that we largely gathered self-report information of service users instead of using assessments by independent researchers. Self-report is sensitive to how questions are asked (formulation and format) and the given context (e.g., the presence of cognitive impairments due to a psychiatric disorder, the actual location (own home, RIRC) where questions are asked) (Schwarz, 1999). Therefore, internationally validated research instruments were used (HoNOS for functioning by Wing, Beevor, Curtis et al, 1998; CANSAS for needs for care by Phelan, Slade & Thornicroft et al, 1995; HAS for helping alliance by Priebe & Gruyters, 1993; MANSA for quality of life by Priebe, Huxley, Knight et al, 1999; CSQ for satisfaction with care by Larsen, Attkisson, Hargreaves et al, 1979) and we trained key workers to use these instruments to report on service users' level of functioning,

needs for care and the helping alliance in a standardized manner. Still, this might not completely compensate for the limitations of self-report, because key workers themselves are also biased by their frame of reference.

Third, we were unable to include community-housing programmes provided by hospital based mental health care services. At face value it seems that housing programmes on hospital premises or in close proximity offer care to more impaired people than those living in RIRCs. However, hospital-based services also run housing programmes in regular neighbourhoods and provide supported independent living in their catchment area. This is a result of mergers between these services and former RIRCs to form large regional mental health services that provide intra- and extramural care and community support. It seems likely that their service users are at least very similar to those of independent RIRCs and that our results are also to a large extent applicable to them. Still, there is a possibility that the service users in hospital-based facilities have easier access to clinical mental health care than do their RIRC peers. This may have positive consequences for their outcomes, such as earlier treatment and easier access to medication, as well as negative consequences, such as less emphasis on social inclusion. This remains an issue to be investigated further.

Discussion of main findings

Deinstitutionalization and its consequences: a European perspective on psychiatric community care provision

Although the deinstitutionalization process is different across European countries, it seems the service-user populations and the questions that they raise about the consequences of deinstitutionalization are quite similar. We found deinstitutionalization to have had little influence on the composition of service-user groups in community housing programmes across countries in terms of socio-demographic and clinical characteristics. In chapters two and three of this thesis, we describe similar residential populations in Italy, England and the Netherlands and also conclude that residents and independently living service users in the latter two countries are similar. Deinstitutionalization did influence the availability of residential beds, which is much higher in the Netherlands than in Italy and England. A study by Priebe, Frottier, Gaddini et al (2008) comparing nine European countries indicated that the Netherlands is among the countries with the highest number of beds available in Europe.

The comparisons described above are informative for the countries involved and shed some light on the consequences of deinstitutionalization for people with SMI in the community. However, these evaluations are limited e.g., by different research designs (e.g. different methods of gathering data, different data sources), different care delivery systems (e.g., different thresholds of access to the mental hospital), and different terminology used to describe housing programmes (e.g., 'floating support programmes' and 'supported independent living programmes'). Other comparative studies into European deinstitutionalization have similar restrictions (Becker & Vazquez-Barquero, 2001; Becker, Hulsmann, Knudsen et al, 2002; Knapp, Beecham, McDaid et al, 2011). There is a call for European research using data collection and monitoring methods that can be used across national borders (Becker & Vazquez-Barquero, 2001; Becker et al, 2002; Fears & Höschl, 2011). With this aim, the EPSILON-study (Becker, Knapp, Knudsen et al, 2000) was the first to validate a set of research instruments (including the CANSAS that was used in the UTOPIA-study presented here) for international use. Still, the focus of the EPSILON-study was on methodology and was not explicitly aimed at a specific mental health sector. To date there is only one three-year pan-European comparative study funded by the European Commission, called DEMoBinc (DEvelopment of a Measure of Best practice for people with long term mental illness in institutional care), which is exclusively aimed at institutional mental health care, including supported housing. A systematic review on what constitutes good care within this study concluded that institutions should ideally be community based, with a flexible organization (Taylor, Killaspy, Wright et al, 2009). The number of residents living together should be low, and service user privacy and autonomy should be a priority. Regular staff supervision, with room for shared decision-making, should be provided and should support positive therapeutic relationships (Taylor, Killaspy, Wright et al, 2009). Results from the UTOPIA study indicate that RIRCs in general meet these criteria (De Heer-Wunderink, Visser, Caro-Nienhuis et al, 2009). Their housing programmes consist of small-scale facilities, varying from individual apartments to single-family homes for three to four residents. Their rehabilitation-oriented care includes a focus on service-user autonomy, privacy and shared decision-making, and service users and key workers generally report positive therapeutic relationships.

The DEMoBinc study provides a tool to compare rehabilitation-oriented care across countries: the QuIRC (Quality Indicator for Rehabilitative Care), an instrument to measure best practice in complex mental health facilities which has demonstrated good content validity, acceptability and inter-rater reliability (Killaspy, White, Wright

et al, 2011; Killaspy, White, Wright et al, 2012). Concerning internal validity, service user ratings of their experiences of care and autonomy also corresponded to the unit managers' QuIRC ratings (Killaspy et al, 2012). This instrument can be used by RIRCs, and other psychiatric community services in the Netherlands and Europe, to measure the recovery orientation of care from a management perspective and to relate this to service-user outcomes. If the QuIRC had been available during the UTOPIA-study, its use would have been an asset. It assesses seven care domains, i.e. Living Environment; Therapeutic Environment; Treatments and Interventions; Self-Management and Autonomy; Social Interface; Human Rights; and Recovery Based Practice. It also collects information on several aspects of psychiatric units, e.g., staffing, environmental and therapeutic aspects.

Nevertheless, the QuIRC is limited to unit management information. A standardized instrument to measure the recovery orientation of the actual care process between service users and key workers is still missing. In the UTOPIA-study we have made a first attempt to develop such a measure. In chapter five of this thesis we describe a method to screen written treatment plans, as a proxy of real treatment, on their adherence to rehabilitation principles. These rehabilitation principles are based on the 'Choose-Get-Keep' model (Anthony, Cohen, Farkas et al, 2002) and are aimed at choosing, getting and keeping a rehabilitation goal. This process includes a service-user centred approach, user involvement in treatment planning, and clearly defining and evaluating rehabilitation goals. This method improves our insight in the way and degree to which an institutional focus on rehabilitation-oriented care (as can be surveyed with the QuIRC) is integrated in the actual care process and therapeutic relationship between service users and key workers. Two-thirds of RIRC treatment plans revealed a sufficient integration of rehabilitation principles. This indicates that the rehabilitation-oriented institutional policy is not a guarantee for full integration of rehabilitation principles in the daily care practice. This implies that additional efforts are needed to achieve this, in terms of training and education of key workers and monitoring the care process. Our method should be investigated further on reliability, practical use and the applicability to housing programmes of Dutch mental hospitals and in other countries.

Recovery oriented community care is expected to have beneficial effects on outcomes for service users. Nevertheless, an evidence base is missing worldwide due to a lack of (R)CTs in this mental health care field (Michon & Van Weeghel, 2008). In this respect, there is a need for equivalent European (R)CTs into community housing programmes to establish the effects of their rehabilitation-oriented care.

Care allocation

In chapter three of this thesis, we discuss the similarity of service users in supported housing and supported independent living programmes in terms of socio-demographic and clinical characteristics in the Netherlands and England. In both countries this raises questions on the effectiveness and accurateness of the care allocation system (Priebe, Saidi, Want et al (2009) and chapter two of this thesis). Perhaps objective criteria are lacking accurately to allocate people to the right type and level of care. It is nevertheless likely that a large proportion of current residents are able to make the transition to an independent living situation, which is discussed in the next paragraph. This is important, especially given that RIRCs are currently pressured by the governmental financial cuts to reconsider their residential population. In 2012 their total budget is being cut by 5% and the rates for RIRC support lowered. They need to find out which service users are able to make this transfer. However, knowledge of how to do this, and additionally of what kind of services should be provided to make such a transition successfully, is unavailable.

The UTOPIA-study provides some clues on which residents might be up to this challenge. Information was gathered on the level of functioning of a representative sample of service users. We established that more than one-third of residents have only mild or subclinical problems in functioning (chapter two of this thesis). Investigating this group in more detail, e.g., on needs for care, the support they receive from formal and informal carers, and their level of social inclusion, can provide some indications on the kind of service users that should actually be considered. Furthermore, research on deinstitutionalization has focused on the transition from hospital to the community. The reconsideration of the RIRCs' residential population and the necessity to identify residents who are able to make the transition to supported independent living presents a unique opportunity to study the possibility and consequences of deinstitutionalization within housing programmes in the local community. The influence of the increase in service-user autonomy (i.e. residing in your own home as a 'normal' person instead of being 'institutionalized' in a residential facility) in terms of recovery, empowerment and social inclusion, on the one hand, and use of additional (mental health and social) care services, rehospitalisation rates and general functioning, on the other, could be the subject of a thorough and worthwhile investigation. This information is valuable not only for the future allocation of people to housing programmes, but also for the way these programmes are organized.

In the UTOPIA study we have established that the number of individual apartments in supported housing has increased in the past years to meet service users' need for privacy and autonomy. In 2006 fourteen RIRCs provided 432 individual supported housing apartments, which increased by 125% to 974 apartments in 2009 (Caro-Nienhuis, De Heer-Wunderink, Sytema et al, 2010). At face value this seems a positive development, but scientific evidence is not yet available. The question remains whether group living arrangements should disappear entirely, or if perhaps the most disabled people still have something to gain from this type of housing, e.g., easier access to staff and social contacts with housemates.

Another important development in the context of care allocation is a change in the funding system for supported independent living programmes in the next two years in the Netherlands. The funding for the care provided by these programmes, which includes psychosocial and practical support, daytime activities and job coaching, is transferred from the national to the local authority. There is a lack of thorough research into this governmental policy and its effects on the daily lives of service users, e.g., on the way care will be provided or on the organization of care providers. The consequences for the service users currently living independently are uncertain. RIRCs will no longer be their apparent care provider, because local policy will determine to a larger extent how certain provisions will be made. For example, the local authority may decide to transfer the support of social and vocational activities from a RIRC to a community centre. Instead of a RIRC key worker, a volunteer and/or informal caregiver may become responsible for aspects of daily support, e.g. shopping for groceries and helping with administration. These new arrangements may lead to fragmentation of care. This in turn may lead to inefficient delivery of care, miscommunication between providers and between providers and users, or even to causing some of the independently living service users to fall along the wayside. For example, a service user who currently receives a meal service at home (in Dutch '*tafeltje dekje*') might be expected to get his meals in a nearby nursing home. Apart from the stigma that is implicitly raised by such a measure, a lot of service users with SMI will probably experience difficulties in undertaking these kinds of activities independently. As a consequence they might not venture out at all. The question is whether these issues are still adequately addressed in a situation of shared responsibility. There is a risk of (in)formal carers waiving the responsibility, leading to attenuation of care. So, before changing the current care system local authorities should be well prepared for their allocation tasks with clear agreements on care responsibilities for all parties involved.

At the same time, the new care system can also hold opportunities for enhancing social inclusion. For example, using a community centre instead of a day centre for daily activities can facilitate contacts with 'normal' neighbours. From previous studies we know that a 'normal' environment has a positive effect on service users concerning (social) functioning (Fakhoury, Murray, Shepherd et al, 2002), hospitalization (Rog, 2004; Shepherd, Muijen, Dean et al, 1996), quality of life (Priebe, Hoffmann, Isermann et al, 2002; Nelson, Sylvestre, Aubry et al, 2007), and satisfaction with care (Fakhoury et al, 2002; Newman, 2001). Therefore, a transition from supervised community housing to living independently could also have beneficial effects. It also meets the preference of many service users themselves for an independent living situation (Warren & Bell, 2000; Tsai, Bond, Salyers et al 2009; Tanzman, 1993). Nevertheless, in the UTOPIA-study we found independently living service users to experience a lower quality of life than residents. Living on your own also entails higher demands, for example, taking responsibility, gaining and keeping social contacts, the ability to take the initiatives to do daily chores and to organize your life. Future research into Dutch community housing programmes should therefore be focused on monitoring the present supported independent living programmes and their service users in time. There is a need to establish the functionality of the current funding system, e.g., in terms of the quality and effectiveness of care provision and service user outcomes (e.g., quality of life, satisfaction with care, functioning, level of social inclusion). This will enable comparisons between the current and the new, locally funded, care system in the future, to assess the real consequences of this policy for service users.

Social inclusion

RIRCs promote themselves as bridge builders between mental health care and society. They distinguish themselves from hospital-based facilities in their focus on service users' possibilities, instead of being dedicated to treating psychiatric symptoms. They put effort into enhancing the social inclusion of their service users, e.g., by providing day centres, sheltered employment and job coaching. In comparison with their European counterparts, RIRCs seem to be relatively successful. More than half of their service users are engaged in paid, voluntary or sheltered employment (chapter two of this thesis). The sheltered employment projects run by RIRCs vary from a bakery, a chore and errand service, a printing office, a catering service, to a Lego® workshop specifically aimed at people with autism. Still, 40% of service users are inactive, and independently living service users do not seem to be more active in vocational activities than residents (chapter four of this thesis). Although RIRCs are off to a good start, it seems their current efforts do not reach everyone with 'job potential'. Only

one in ten service users is in paid employment, while about one-third of the service users has mild or subclinical problems in functioning. This seems to offer the possibility that more service users are indeed able to acquire a paid job, given that they are provided with the adequate support to do so. As stated in chapter four, RIRC support still appears to be mainly focused on providing 'something to do', instead of on working towards regular employment. Evidence based interventions, such as Individual Placement and Support (IPS; Burns, Catty, White et al, 2009) that help people with SMI to acquire and maintain a regular paid job, are not a standard service. There might be a lot to be gained in this area. At least some of the people who are currently in sheltered or voluntary employment are able and willing to make the transition to a paid job (De Heer-Wunderink et al, 2009). It could be worthwhile to identify these service users and find out which support is needed to guide them there.

Another associated impediment for social inclusion is the lack of sufficient qualifications to acquire a paid job. This is the case for about 40% of residents and 35% of independently living service users (De Heer-Wunderink et al, 2009). The education of people with SMI is underexposed in research and in mental health policy and practice. In the past decade, there have been some studies on Supported Education in the US (e.g. Mowbray, Collins, Bellamy et al, 2005; Mowbray, Gutierrez, Bellamy et al, 2003; Bybee, Bellamy & Mowbray, 2000; Best, Still & Cameron, 2008; Unger, Pfaltzgraf & Nikkel, 2010; Unger & Pardee, 2002) and also one international comparison between the US and the Netherlands (Mowbray, Korevaar & Bellamy, 2002). These studies indicate that such an intervention, which gives people with SMI the opportunity to study at a normal school with support, may prove to be an important contributor in improving the educational attainment of service users, and thereby their job perspective (Mowbray, 2000; Mowbray et al, 2002; Murphy, Mullen & Spagnolo, 2005).

When discussing social inclusion, it is unjust to discuss RIRC care provision alone. The broader social and economic context should also be taken into account. Especially now, in times of economic crisis and (mental) health care cuts, it seems the most vulnerable people have to foot the bill for it. The majority of mental health service users are dependent on a small income. Of the 160,000 Dutch people with SMI, 83% live on or under the poverty line (GGZ Nederland, 2011). This is in itself a barrier for social inclusion. From this income, residents as well as independently living service users pay a statutory contribution for the care they receive under the Exceptional Medical Expenses Act (Dutch acronym: AWBZ). The Dutch government has decided that from 2012 these people also have to pay a statutory contribution for secondary

mental health care. This contribution is 145 euro for residents and between 100 and 200 euro for independently living service users. Furthermore, the government does not impose such measures for somatic care by specialized physicians. The disadvantages for social inclusion are twofold: first, this is a discriminatory measure that sets people with SMI apart from people with physical disabilities, and second it sets back their social inclusion financially. Furthermore, this strategy also raises a financial barrier for the access to needed care and supports. People may choose not to seek mental help, possibly leading to more serious untreated mental health problems, more social inconvenience and dangers to society. The Dutch national institute for mental health and addiction, the Trimbos Institute, has estimated a possible increase in social costs of up to 375 million euro due to this measure. Although social inclusion of people with SMI is a priority of the Dutch Mental Health Care Association, the current political measures may render opposite effects. This issue should be investigated further through establishing the current level of social inclusion of service users and monitoring its change over time in relation to the measures discussed.

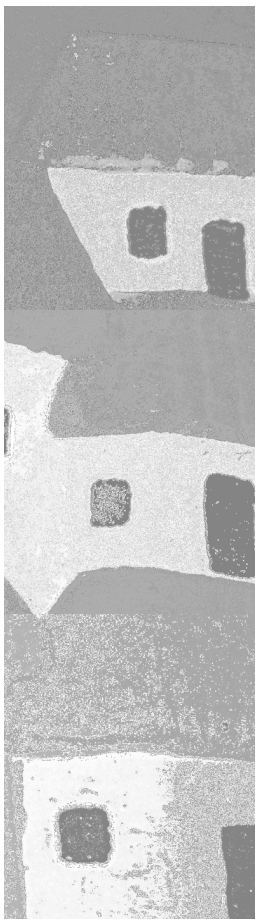
Implications for future research

Research into deinstitutionalization should focus on the recovery orientation of community mental health services, from a management as well as from a care perspective. This focus is essential because of the emphasis of recovery on promoting service user autonomy, independence and social inclusion, which are important goals of current European as well as Dutch mental health care policy. The effects of recovery-oriented community mental health care on outcomes for service users should be investigated through European research, using data collection and monitoring methods that can be used across national borders. These service-user outcomes should also include medical aspects such as somatic needs and side effects of medication, to establish the extent to which there is adequate attention for these treatment like needs in RIRC support.

In the Netherlands, the RIRCs and their service users have to be compared with hospital based community housing programmes and their service users to assess (dis)similarities in the focus of and access to care, in the organization of housing programmes, in service users' socio-demographic and clinical characteristics etc. Effect studies should be conducted to determine if these types of care render different

results in terms of e.g., satisfaction with care, service user functioning, and needs for care and social inclusion.

Finally, future studies on RIRC care need to investigate the reconsideration of their residential population and the resulting transfer of residents to an independent living situation. In addition, the consequences of governmental policy (e.g., changing the funding structure for supported independent living programmes) should be closely monitored to determine the long-term effects of these measures on outcomes for service users.



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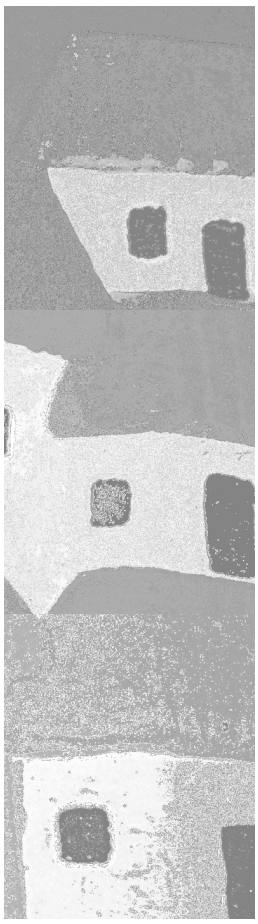


Summary

Chapter 1 Introduction

The first asylums for people with severe mental illness, who were at that time depicted as lunatics, were developed as early as 1403 in England. These asylums often resembled prisons and in general conditions were harsh. It was only in the first half of the twentieth century that asylums started to make the transition to 'mental hospitals'. In the 1950's some of the largest European mental hospitals had up to 4,000 beds. In this period the awareness grew that these hospitals were too large and isolated. People with SMI should be supported in their own community, with an emphasis on prevention and rehabilitation and the aim to improve their social integration. This transfer of long-term mental health care from the hospital to the community is referred to as deinstitutionalization. In the Netherlands this process advanced gradually. In 1971 the Hospital Act initiated a policy that promoted smaller, regional psychiatric services and discouraged the use of the old and large mental hospitals. In 1983, the Chief Medical Inspectorate for Mental Health Care advocated for the development of so called Regional Institutes for Residential Care (RIRCs; Dutch acronym RIBW) that should provide housing to former mental hospital patients. However, the economic recession in the 1980's and the ability of mental hospitals to oppose substitution of hospital- for RIRC beds and to develop and increase their own outpatient care slowed down this process. In the 90's RIRCs were able to progress through rearrangement of funds for care innovation.

To date there are 21 RIRCs that provide supported housing to more than 8,061 residents and support more than 9,943 independently living people with SMI. RIRCs have developed into a distinctive mental health sector. They distinguish themselves from hospital-based facilities in their focus of care, which is based on Psychiatric Rehabilitation principles. This entails that RIRCs do not treat psychiatric symptoms, but help their service users enhance their self-help skills and promote their social inclusion. RIRCs define their institutes as bridge-builders between mental health care services on the one hand and society on the other. In this capacity, they provide day centres, sheltered employment projects and job coaching. Research into supported housing programs is steadily growing.

In Italy and the UK, where deinstitutionalization was executed drastically, respectively the PROGRES study and TAPS project have succeeded in monitoring and reporting on deinstitutionalization. The UTOPIA study, from which results are described and discussed in this thesis, investigates deinstitutionalization in the

Netherlands illustrated by RIRC care. The UTOPIA study consists of two phases. The first phase started in 2006 to 2007 and comprised an administrative data assembly including all 21 RIRCs. They provided information on their institutions (production, growth, care provision) as well as socio-demographic, clinical and care characteristics of all of their service users in supported housing and supported independent living programs. This exercise was repeated in 2009 to gain insight in the RIRCs' institutional developments and changes in their service user population over the years. In the second phase, which was executed from 2007 to 2009, 16 RIRCs participated in a large-scale cross-sectional survey including a random sample of 119 key workers and 818 of their service users. We investigated their level of functioning, needs for care, helping alliance, quality of life, satisfaction with care and social inclusion.

Chapter 2 *Residential care: Dutch and Italian residents of residential care facilities compared*

As mentioned in the introduction, deinstitutionalization in Italy has been more far-reaching compared to the Netherlands. Where in our country community care has developed alongside the mental hospital, in Italy access to all mental hospitals were closed. At face value, one could argue that these different reform processes have consequences for the people who are in need of community services. In the Netherlands, the most vulnerable people can still be allocated to a hospital long stay ward, whereas in Italy these people have to be cared for in residential facilities. In this chapter, we compare Dutch residents to their Italian counterparts to establish if these countries indeed have different residential populations. We used data from the first phase of the UTOPIA study (n=1656) and the Italian PROGRES study (n=2962) to compare service users on socio-demographic, clinical and care characteristics. The Dutch and Italian residential populations proved to be quite similar, although substance use disorders are more frequent in the first. This may indicate a more restrictive policy towards substance abuse in the Italian facilities. Italian residents were more likely to be diagnosed with schizophrenia and showed an overall shorter duration of stay. Perhaps Italian residents, who live in a culture with strong family relations, have a more available and effective social network that makes discharge more likely. Also, the number of beds in residential care facilities per 10,000 inhabitants is twice as high in the Netherlands (6) compared to Italy (3). The shorter duration of stay in Italy could therefore also reflect a higher turnover rate, pressured by the less availability of residential beds. Contrary to our expectations Dutch residents, who still have good access to long

stay beds in mental hospitals, are not less disabled than Italian residents. The difference in total mean GAF-scores, although statistically significant, was not clinically relevant. We conclude that although the Italian and Dutch deinstitutionalization processes have resulted in a different availability in the number of residential beds, it did not influence the composition of both residential populations.

Chapter 3 *Supported Housing and Supported Independent Living in The Netherlands, with a comparison with England*

Recently, Priebe et al (2009) found a considerable overlap of characteristics of service users and care provision between supported housing and supported independent living programs. They raise the question whether their care allocation system benefits from the flexibility to provide the right level of care to individuals, or that the system lacks objective criteria that are needed to guarantee a methodical and structural assessment of potential service users in the allocation procedure. In chapter three, we investigate the characteristics of Dutch service users in supported housing (n=332) and supported independent living (n=202) that may predict their allocation to either of these programs e.g., gender, age, diagnosis, employment status, needs for care and quality of life. We aim to establish whether the English care allocation questions also apply to the Netherlands. Additionally, a comparison is made between Dutch and English residents and independently living service users. We found the differences between Dutch residents and independently living service users to be much smaller than one would expect. Participation in occupational activities, attending a day centre, number of (unmet) needs and quality of life do not differ greatly. This calls the Dutch allocation system to housing programs into question. Moreover, more than one-third of Dutch residents in supported housing have at most mild functional problems (according to their HoNOS scores). This suggests that at least a part of these people might currently receive a higher level of care than is actually required, and perhaps also wished for by residents themselves. Taking the long and persisting waiting lists for residential care and the recent cuts in the mental health care budget into account, this is a matter that RIRCs are now taking into account.

As regards to the comparison with their English counterparts, the service user population in in England differs to some extent from that in The Netherlands, with respect to gender (more males), civil status (more persons who have never been

married) and diagnosis (more persons with schizophrenia). This suggests that the English service users are more similar to the long stay population from the closed or reduced mental hospitals. Furthermore, Dutch RIRCs seem to be able to address the needs of their service users more efficiently. The latter have more met needs and are more engaged in occupational activities than their English counterparts. Yet, more information is needed about the level of functioning of the latter to substantiate these findings.

Chapter 4 *Social Inclusion of People with Severe Mental Illness Living in Community Housing Programs*

Previous studies have indicated that social inclusion of people with SMI is far from successful. A large proportion spend a substantial amount of their time passive, sleeping or with self-care activities. In 2009, the Dutch Mental Health Association published a report stating their aim for enhancing recovery and citizenship for people with SMI, of which housing is an important part. This national approach is in line with priorities stated in 2010 by the Federation of the European Academies of Medicine (FEAM) for European mental health care, which include tackling stigma and problems associated with employment for people coping with SMI.

In this chapter we explore the social inclusion of service users of supported housing and supported independent living programs, demonstrated by diaries. We asked service users to keep a diary for one week. Every day, they had to report every four hours what they were doing, with whom and where. They also rated each day on a scale from 0 (couldn't be worse) to 10 (couldn't be better), as an indicator of satisfaction with daily life. A random sample of 255 diaries were screened with a focus on three aspects of social inclusion: 1) 'activities', alone and with others, 2) 'visits' to and from other people and 3) 'vocational participation', yes or no. Additionally, we examine the relationship between type of housing program and the level of social inclusion.

We found independently living service users to be more likely to be socially included, in terms of activities and visits, than people living in supported community-housing programs. We did not establish a difference between the levels of participation in more competitive activities, such as paid employment. In both housing programs, only eight per cent of service users have a regular paid job and roughly 40% of service users are not in any way employed. Additionally, independently living service users are less satisfied with their daily life and report

a higher total mean number of unmet needs, especially in the area of social contacts. We conclude that the future challenge for mental health services, policy makers, professionals, service users and advocates, lies in improving the level of vocational participation of service users in both programs. Additional resources, such as Supported Education and Supported Employment programs, need to be made more readily available to people with SMI to improve their chances of social inclusion.

Chapter 5 *Treatment plans in Psychiatric Community Housing Programs: do they reflect Rehabilitation Principles?*

In both the US and Western Europe, rehabilitation and recovery have increasingly become key principles in the care for people with severe mental illnesses (SMI). Recovery denotes the individual, personal process that people with SMI experience while rehabilitation is what services do to facilitate recovery. Evidence on rehabilitation-based housing programs on improving outcome of their service users is limited. Also, across psychiatric settings information about the extent to which rehabilitation principles are actually adhered to is lacking. The Choose-Get-Keep model of psychiatric rehabilitation, developed by the Centre for Psychiatric Rehabilitation in Boston, provides rehabilitation program standards and includes guidelines for documenting rehabilitation goals. This offers the opportunity to use these guidelines to screen treatment plans on their adherence to rehabilitation principles.

In chapter five, we describe a new method to screen treatment plans on adherence to rehabilitation principles. These plans (n=240) are judged on 10 Rehabilitation criteria: 1) Are rehabilitation goals formulated? , 2) Is space reserved for written service user consent?, 3) Is an evaluation date planned?, 4) Is the plan written in the first person, reflecting a service user-centred approach?, 5) Are emergency agreements available in case of a crisis?, 6) Can we identify the rehabilitation phase of a goal?, 7) Is there a time stipulated for evaluation of goal attainment?, 8), Which parties are involved?, 9) Is there a clear division of tasks among the parties involved, and 10) Is the role of the service users' key worker clearly defined? When met, each of these criteria is awarded one rehabilitation point, resulting in a minimum score of 0 (no adherence to rehabilitation principles) and a maximum score of 10 (complete adherence). In addition, we explored whether adherence of treatment plans to rehabilitation principles is related to the service user- and key worker-perspective on unmet needs for care. Rehabilitation oriented care is

service user-centred and also involves shared decision making, i.e. service users and key workers make mutual decisions about support in an equal relationship. One would expect that an increase in adherence to this principles, will lead to a higher correspondence between treatment plan goals and reported unmet needs. Our results indicated that the mean adherence score of treatment plans is 6.8 (sd 1.9, median 7.3). Two thirds of treatment plans (66%, n=158) show a sufficient degree of adherence to rehabilitation principles, which means they have a rehabilitation score of at least seven out of ten. However, we could not establish a relationship between a higher level of adherence to rehabilitation principles and a better integration of unmet needs in treatment plans. The main limitation of this study was that we were unable to measure the adherence to rehabilitation principles of the actual care provision. Future research should address this, to overcome the inconsistencies between the paper plan (treatment product) and the actual care (treatment process).

Chapter 6 *The Role of Helping Alliance in Psychiatric Community Housing Programs: a large-scale cross-sectional survey*

Helping alliance between practitioners and service users is considered essential for improving treatment outcomes across mental health care settings. Although previous studies have established that the helping alliance contributes to better treatment outcomes in community psychiatry, these studies have mainly focused on (assertive) community case management. Research into helping alliance in psychiatric community housing programs is largely lacking. In this chapter, the strength of helping alliance and its relationship with service user level of functioning and (agreement on) needs for care of service users (n=584) and key workers (n=105) in supported housing and supported independent living programs is investigated. Furthermore, the influence of care intensity (i.e. the difference between supported housing and supported independent living) on the relationship between helping alliance and service user outcomes is examined. In both housing programs, a stronger helping alliance is associated with less unmet needs for care. In supported housing, an increase in helping alliance is also associated with more agreement between service users and key workers on needs for care. It is likely that frequency and intensity of therapeutic contact are important for the latter association. The higher dependency on care or support provided by others in supported housing programs will enhance the influence of this support on daily life. It will also increase the need to reach consensus about the direction of support.

Our findings suggest that investing in the therapeutic relationship is a means to reduce service users' unmet needs in community housing programs. In supported housing, the quality of the therapeutic relationship also contributes to the agreement between service users and key workers on the needs that should be addressed.

Chapter 7 General Discussion

In this chapter we describe the strengths and limitations of the UTOPIA study and discuss the main findings of this thesis, illustrated by three central themes. The first is '*deinstitutionalization and its consequences: a European perspective on psychiatric community care provision*'. In chapter two and three, we found that service users of community housing programs are quite similar between European countries, despite different deinstitutionalization processes. However, these comparisons are limited by different terminology, various research designs etc. A recent pan-European study (DEMoBinc) developed a toolkit to compare quality of care between countries and to relate that to service user outcomes such as autonomy and quality of life. Although this provides valuable information on European institutional care, the supported independent living programs have been left out. Furthermore, research into and measures for the actual daily care in housing programs are missing. We have made a first attempt to develop such a measure within the UTOPIA study (chapter five of this thesis). Nevertheless, this method only applies to a written product (the treatment plan) and not the actual care practice. The actual RIRC support should be examined accordingly, and in addition comparisons should be made between the Dutch results and foreign housing programs. This will improve the international insight in how community care is actually provided to the service user and to what degree rehabilitation–oriented care is truly put in practice. This information is currently lacking.

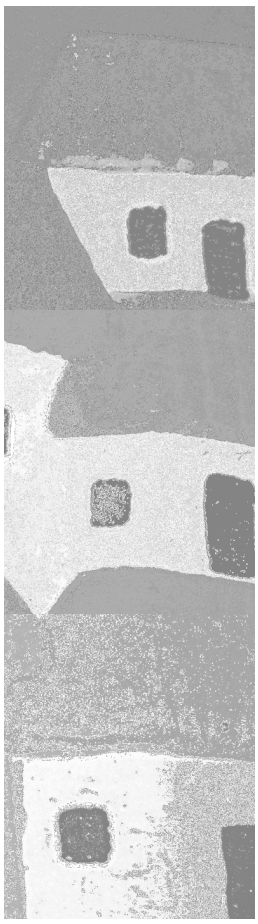
The second central theme is '*care allocation*'. In chapter three of this thesis, we discuss the similarity of service users in supported housing and supported independent living programs in terms of socio-demographic and clinical characteristics. This finding makes it likely that a large part of current residents is able to make the transition to an independent living situation. This is important, especially given that RIRCs are currently pressured by the governmental cuts to reconsider their residential population. Until now, research in deinstitutionalization has focused on the transition from hospital to community, instead of on large-scale within-community transfers. If this transition will take

place in the Netherlands, it presents the unique opportunity to study this process and to gain insight in the consequences of increasing autonomy for service users in terms of their recovery, empowerment and social inclusion. This information is valuable not only for the future allocation of people to housing programs, but also for the way these programs are organized. Furthermore, the funding system for supported independent living programs will change in the coming years. The consequences of this policy for service user outcomes should be carefully monitored in the future.

The third and final theme is '*social inclusion*', which has been far from successful for people with SMI worldwide. RIRCs take effort in enhancing the social inclusion of their service users, and in comparison with their European counterparts they seem to be relatively successful. More than half of their service users are engaged in paid, voluntary or sheltered employment. Still, their support seems to be mainly focused on providing 'something to do', instead of on working towards regular employment. Another impede for social inclusion is the lack of sufficient qualification to acquire a paid job for about 40% of residents and 35% of independently living service users. The education of people with SMI is underexposed in research, mental health policy and practice. Integrating evidence based interventions, such as Individual Placement and Support (IPS) and Supported Education programs into RIRC care might increase job and study tenure of their service users. However, social, cultural and economic factors should also be taken into account. Of the total number of 160.000 people with SMI in the Netherlands, 83% lives on or under the poverty line. This is in itself a barrier for social inclusion. It does not hold back the Dutch government to raise the statutory contribution for secondary mental health care, creating another and financial barrier to social inclusion and moreover to needed care.

Finally, implications for future research are discussed. In a European perspective, research into (the effects of) recovery-oriented community care is needed, using data collection and monitoring methods that can be used across national borders. In the Netherlands the housing programs of RIRCs and mental hospitals should be compared to assess (dis)similarities in the focus and execution of care and characteristics of their service user populations. Also, effect studies should be conducted to determine if these types of care render different results in terms of service user outcomes. Furthermore, future studies on RIRC care need to investigate the reconsideration of their residential population and the consequences of governmental policy (e.g., changing the funding structure for

supported independent living programs) for service user outcomes on the long run.



Samenvatting

Hoofdstuk 1 Introductie

De eerste krankzinnigengestichten voor mensen met een psychiatrische ziekte, die in die tijd werden aangeduid als gekken, werden al in 1403 opgericht in Engeland. Deze gestichten deden vaak denken aan gevangenissen en over het algemeen waren de omstandigheden voor de bewoners slecht. Pas in de eerste helft van de twintigste eeuw vond er een overgang plaats van 'het gesticht' naar 'het psychiatrisch ziekenhuis'. Rond 1950 kon het aantal bedden van de grootste psychiatrische ziekenhuizen in Europa lopen tot 4,000. In deze periode groeide het bewustzijn dat deze ziekenhuizen te groot en geïsoleerd waren. Mensen met een psychiatrische ziekte zouden moeten worden geholpen in hun eigen omgeving, met een nadruk op preventie en rehabilitatie en met de doelstelling hun maatschappelijke integratie te verbeteren. Deze overgang van de langdurige geestelijke gezondheidszorg van het ziekenhuis naar de samenleving wordt ook wel deïnstitutionalisatie genoemd. In Nederland verliep dit proces heel geleidelijk. In 1971 initieerde de Wet Ziekenhuisvoorzieningen beleid dat gericht was op kleinere, regionale psychiatrische instellingen en de ontmoediging van gebruik van de grotere en oudere psychiatrische ziekenhuizen. In 1983 pleit de Geneeskundige Hoofdinspectie voor de Geestelijke Volksgezondheid voor de ontwikkeling van zogenaamde Regionale Instellingen voor Beschermd Wonen (RIBW's), die moeten zorgen voor de huisvesting van psychiatrische patiënten uit het ziekenhuis. De economische recessie in de jaren tachtig, en de macht van de ziekenhuizen om zich te verzetten tegen het vervangen van hun eigen bedden voor RIBW-bedden en de mogelijkheid om zelf ambulante zorg te ontwikkelen en uit te breiden, vertraagt deze ontwikkeling echter. In de jaren negentig kunnen RIBW's zich verder ontwikkelen door een substitutieregeling waardoor financiële middelen voor bestaande zorg kunnen worden gebruikt voor zorgvernieuwing.

Tegenwoordig zijn er 21 RIBW's die begeleiding bieden aan meer dan 8,061 mensen die beschermd wonen en meer dan 9,943 mensen die begeleid zelfstandig wonen. RIBW's hebben zich ontwikkeld tot een eigen sector binnen de geestelijke gezondheidszorg. Ze onderscheiden zichzelf van reguliere GGZ-voorzieningen in de nadruk die ze in hun begeleiding leggen op Rehabilitatie principes. Dit houdt in dat RIBW's geen psychiatrische symptomen behandelen, maar zich richten op het vergroten van de zelfredzaamheid en maatschappelijke integratie van hun cliënten. In deze hoedanigheid bieden zij ook dagactiviteitencentra, beschermde werkvoorzieningen en trajectbegeleiding.

Het onderzoek naar woonvoorzieningen voor mensen met psychiatrische problemen neemt geleidelijk toe. In Italië en Engeland, waar de deïnstitutionalisering veel drastischer heeft plaatsgevonden, zijn respectievelijk de PROGRES-studie en de TAPS-studie er in geslaagd dit proces te volgen en vast te leggen. De UTOPIA-studie, waarvan resultaten worden beschreven en besproken in dit proefschrift, onderzoekt de deïnstitutionalisering in Nederland aan de hand van de RIBW's. De UTOPIA-studie bestaat uit twee fasen. De eerste fase bestond uit een prevalentiemeting. Vanaf 2006 tot 2007 werden van alle RIBW's administratieve gegevens verzameld over hun instelling (productie, groei, zorgaanbod), naast sociodemografische, klinische en zorggegevens over hun cliënten. Deze gegevensverzameling werd in 2009 herhaald teneinde inzicht te krijgen in de ontwikkelingen van de RIBW-sector op instellings- en cliëntniveau in de loop der jaren. De tweede fase van het onderzoek werd uitgevoerd tussen 2007 en 2009. Zestien RIBW's participeerden in een grootschalige cross-sectionele survey met behulp van 119 persoonlijk begeleiders en 818 van hun cliënten. We hebben in deze fase het niveau van functioneren, zorgbehoeften, de begeleidingsrelatie, kwaliteit van leven en maatschappelijke integratie van cliënten onderzocht.

Hoofdstuk 2 *Residentiële zorg: een vergelijking tussen Nederlandse en Italiaanse cliënten in beschermende woonvormen*

Zoals eerder vermeld in de introductie is de deïnstitutionalisering in Italië veel drastischer verlopen dan in Nederland. Waar in ons land residentiële en ambulante zorg zich ontwikkelde naast de reeds bestaande ziekenhuiszorg, werd in Italië de toegang tot het psychiatrische ziekenhuis afgesloten. Op het eerste gezicht is het te beargumenteren dat deze verschillende hervormingsprocessen gevolgen hebben gehad voor de mensen die van deze zorg gebruik maken. In Nederland kunnen de meest kwetsbare mensen nog steeds terecht op een afdeling voor langdurige zorg van het psychiatrisch ziekenhuis, terwijl deze mensen in Italië worden verzorgd in residentiële voorzieningen. In dit hoofdstuk vergelijken we Nederlandse residentiële cliënten met hun Italiaanse tegenhangers om vast te stellen of er inderdaad sprake is van verschillende cliëntenpopulaties. We hebben gegevens gebruikt van de eerste fase van de UTOPIA-studie (n=1656) en de Italiaanse PROGRES-studie (n=2962) om cliënten te vergelijken op sociodemografische, klinische en zorg kenmerken. De Nederlandse en Italiaanse residentiële populaties bleken erg overeen te komen, hoewel er in de eerste groep vaker verslavingsproblematiek voorkomt. Dit zou kunnen wijzen op een strenger toelatingsbeleid in Italiaanse instellingen. Italiaanse residentiële cliënten zijn vaker gediagnosticeerd met schizofrenie en hebben een

kortere verblijfsduur. Misschien hebben Italianen, van wie de cultuur sterk gericht is op familiebanden, een makkelijker beschikbaar en effectiever sociaal netwerk dat de kans op ontslag vergroot. Daarnaast is het aantal bedden in beschermende woonvormen per 10,000 inwoners twee keer zo groot in Nederland als in Italië (6 vs. 3). De kortere verblijfsduur in Italië kan dus ook een weerspiegeling zijn van snellere doorstroom onder druk van beddenschaarste. Tegen onze verwachting in functioneren Nederlandse residentiële cliënten, die nog steeds toegang hebben tot het psychiatrisch ziekenhuis, niet slechter dan Italiaanse residentiële cliënten. Het verschil in GAF-scores was statistisch significant, echter zonder klinische relevantie. We concluderen dat het deïnstitutionaliseringsproces wel invloed heeft gehad op de beschikbaarheid van het aantal residentiële bedden, echter niet op de samenstelling van de residentiële cliëntenpopulaties.

Hoofdstuk 3 *Beschermd wonen en begeleid zelfstandig wonen in Nederland, met een vergelijking met Engeland*

Recent onderzoek van Priebe et al (2009) heeft uitgewezen dat de cliënt- en zorgkenmerken van het beschermd wonen (BW) en begeleid zelfstandig wonen (BZW) elkaar aanzienlijk overlappen. Het is de vraag of er sprake is van een systeem van zorgtoewijzing dat juist door flexibiliteit in staat is de juiste zorg toe te wijzen aan individuen, of dat dit systeem objectieve criteria mist die garanderen dat aankomende cliënten methodisch en structureel beoordeeld worden. In hoofdstuk drie onderzoeken we de kenmerken van Nederlandse BW-cliënten (n=332) en BZW-cliënten (n=202) die mogelijk voorspellers zijn van de zorgtoewijzing naar een van deze programma's, bijvoorbeeld geslacht, diagnose, werksituatie, zorgbehoeften en kwaliteit van leven. Het doel is vast te stellen of het Engelse zorgtoewijzingsvraagstuk ook van toepassing is op Nederland. Daarnaast vergelijken we Nederlandse en Engelse residentiële en zelfstandig wonende cliënten.

De gevonden verschillen tussen Nederlandse BW- en BZW-cliënten waren kleiner dan verwacht. Deelname aan beroepsgerichte activiteiten (bijv. allerlei vormen van werk), het bezoeken van een dagactiviteitencentrum (DAC), het aantal (onvervulde) zorgbehoeften en kwaliteit van leven verschillen nauwelijks. Dit roept vragen op ten aanzien van het Nederlandse zorgtoewijzingssysteem. Bovendien heeft meer dan een derde van de Nederlandse BW-cliënten op z'n hoogst milde functioneringsproblemen (volgens hun HoNOS-scores). Dit lijkt erop te wijzen dat op z'n minst een deel van deze mensen mogelijk meer zorg krijgt dan noodzakelijk, en misschien ook meer dan cliënten zelf zouden willen. Rekening houdend met de lange en hardnekkige

wachtlijsten voor deze vorm van begeleiding en de recente bezuinigingen op de GGZ, is dit een bevinding waar de RIBW's inmiddels rekening mee houden.

Ten aanzien van de vergelijking tussen Nederland en Engeland lijkt de laatste cliëntenpopulatie iets te verschillen van de eerste op het gebied van geslacht (meer mannen), burgerlijke staat (meer ongehuwde personen), en diagnose (meer mensen met schizofrenie). Dit doet vermoeden dat de Engelse cliënten meer lijken op de langdurige zorg populatie uit de gesloten of in aantal afgenomen psychiatrische ziekenhuizen. Verder lijken Nederlandse RIBW's er beter in te slagen de zorgbehoeften van hun cliënten tegemoet te komen. Nederlandse cliënten hebben meer vervulde zorgbehoeften en doen vaker beroepsgerichte activiteiten dan hun Engelse tegenhangers. Er is echter meer informatie nodig met betrekking tot het functioneringsniveau van de Engelse cliënten om deze bevindingen te staven.

Hoofdstuk 4 *Sociale inclusie van mensen met een ernstige psychiatrische ziekte in woonzorg programma's in de samenleving*

Eerdere studies hebben aangetoond dat de sociale inclusie (ook wel maatschappelijke integratie genoemd) van mensen met ernstige psychiatrische ziekten verre van succesvol is. Een groot deel van deze mensen brengt zijn tijd door met slapen, passieve of zelfzorg activiteiten. In 2009 publiceerde de GGZ Nederland een rapport waarin zij zich als doel stelde het herstel en burgerschap van mensen met ernstige psychiatrische ziekten, waar huisvesting een belangrijke rol in speelt, te vergroten. Deze nationale benadering is in overeenstemming met de prioriteiten van de Federatie van de Europese Academies voor Geneeskunde (FEAG), die het aanpakken van stigmatisering en problemen geassocieerd met werken voor mensen met mensen met ernstige psychiatrische ziekten omvatten.

In dit hoofdstuk onderzoeken we de sociale inclusie van BW- en BZW-cliënten aan de hand van dagboeken. We hebben cliënten gevraagd een week lang een dagboek bij te houden. Elke dag moesten zij opschrijven wat ze deden, met wie en waar. Ze gaven elke dag ook een cijfer op een schaal van 0 (kan niet slechter) tot 10 (kan niet beter), als een indicatie van hun tevredenheid over hun dagelijkse leven. Een gerandomiseerde steekproef van 255 dagboeken werden gescreend met een nadruk op drie aspecten van sociale inclusie: 1) activiteiten, alleen en met anderen, 2) bezoeken aan en van anderen en 3) een vorm van werk, ja of nee. Daarnaast onderzoeken we de relatie tussen het type zorgprogramma (BW of BZW) en het niveau van sociale inclusie. Uit onze resultaten bleek BZW-cliënten meer kans hadden

op sociale inclusie dan BW-cliënten op het gebied van activiteiten en bezoeken. We konden geen verschil vaststellen tussen het niveau van participatie in meer competitieve activiteiten, zoals betaald werk. In beide cliëntenpopulaties heeft slechts acht procent van de cliënten een betaalde baan en ruwweg 40% van de cliënten heeft geen beroepsgerichte bezigheden. Daarbij zijn BZW-cliënten minder tevreden met hun leven en rapporteren zij een hoger aantal onvervulde zorgbehoeften dan BW-cliënten, met name op het gebied van sociale contacten. We concluderen dat de toekomstige uitdaging voor instellingen voor geestelijke gezondheidszorg, beleidsmakers, professionals, cliënten en belangenbehartigers ligt in het vergroten van de deelname aan beroepsgerichte activiteiten van beide cliëntenpopulaties. Om hun kansen op sociale inclusie verder te vergroten, dienen interventies zoals Begeleid Leren en Begeleid Werken makkelijker beschikbaar te worden voor mensen met ernstige psychiatrische ziekten.

Hoofdstuk 5 *Begeleidingsplannen in de RIBW: voldoen zij aan Rehabilitatie principes?*

In zowel de VS als West Europa zijn rehabilitatie en herstel in toenemende mate centrale begrippen in de zorg voor mensen met ernstige psychiatrische ziekten. De term herstel verwijst naar het individuele, persoonlijke proces dat deze mensen doormaken, terwijl met de term rehabilitatie datgene wordt aangeduid dat instellingen doen om herstel te bevorderen. Het bewijs dat rehabilitatie georiënteerde woonzorg bijdraagt aan het verbeteren van de uitkomsten voor hun cliënten is beperkt. Daarnaast ontbreekt informatie over de mate waarin rehabilitatie principes daadwerkelijk toegepast worden volledig. Het Kiezen-Verkrijgen-Behouden model van Psychiatrische Rehabilitatie, ontwikkeld door het Centrum voor Psychiatrische Rehabilitatie in Boston, biedt standaarden voor Rehabilitatie programma's en richtlijnen voor het vastleggen van rehabilitatiedoelen. Dit biedt de mogelijkheid om deze richtlijnen te gebruiken voor het screenen van begeleidingsplannen op hun mate van integratie van rehabilitatie principes.

In hoofdstuk vijf beschrijven we een nieuwe methode om begeleidingsplannen te screenen op hun mate van integratie van rehabilitatieprincipes (de rehabilitatie oriëntatie). Deze plannen (n=240) zijn beoordeeld op tien Rehabilitatie criteria: 1) Zijn rehabilitatiedoelen geformuleerd?, 2) Is er ruimte voor de handtekening van de cliënt?, 3) Is er een datum gepland voor evaluatie van het plan?, 4) Is het plan geschreven in de ik-vorm, wat aangeeft dat de cliënt centraal staat?, 5) Zijn er crisisafspraken?, 6) Is de rehabilitatiefase van het doel duidelijk?, 7) Is er een periode

vastgesteld om te evalueren of een bepaald doel gehaald is?, 8) Zijn de betrokken partijen duidelijk herkenbaar?, 9) Is er een duidelijke taakverdeling tussen de betrokkenen?, en 10) Is de rol van de persoonlijk begeleider van de cliënt duidelijk gedefinieerd? Voor ieder vervuld criterium werd één rehabilitatiepunt toegekend, resulterend in een minimum score van 0 (geen rehabilitatie oriëntatie) tot een maximum score van 10 (complete rehabilitatie oriëntatie). We hebben ook gekeken of de mate waarin een plan voldoet aan rehabilitatieprincipes gerelateerd is aan het perspectief van cliënten en persoonlijk begeleiders op onvervulde zorgbehoeften. Rehabilitatie georiënteerde zorg stelt de cliënt centraal en houdt in dat er een gelijkwaardige relatie bestaat tussen cliënt en begeleider waarin gezamenlijke beslissingen worden genomen over de begeleiding. Op basis hiervan is het te verwachten dat er een hogere overeenstemming is tussen begeleidingsdoelen en onvervulde zorgbehoeften naarmate er in het plan beter voldaan wordt aan rehabilitatieprincipes.

Onze resultaten toonden aan dat de gemiddelde 'rehabilitatie score' van de begeleidingsplannen 6.8 (sd 1.9, mediaan 7.3) was. Tweederde (66%, n=158) van de plannen waren voldoende rehabilitatie georiënteerd, wat een rehabilitatiescore van minstens zeven betekent. We konden echter geen relatie vaststellen tussen de mate van rehabilitatie oriëntatie van het begeleidingsplan en de mate waarin onvervulde zorgbehoeften in dit plan waren verwerkt. De grootste beperking van deze studie ligt in het feit dat het niet mogelijk was om de rehabilitatie oriëntatie van de daadwerkelijke begeleiding kaart te brengen. Toekomstig onderzoek moet hier aandacht aan besteden, om de inconsistenties tussen het papieren begeleidingsplan (het begeleidingsproduct) en de daadwerkelijke zorg (het begeleidingsproces) in kaart te brengen.

Hoofdstuk 6 *De rol van therapeutische alliantie in woonzorgprogramma's in de samenleving: een grootschalige cross-sectionele survey*

Therapeutische alliantie tussen professionals en cliënten speelt een belangrijke rol in het verbeteren van behandeluitkomsten voor cliënten in de geestelijke gezondheidszorg. Hoewel eerdere studies hebben vastgesteld dat therapeutische alliantie bijdraagt aan betere behandelresultaten in de sociale psychiatrie, hebben deze studies zich vooral gericht op case management en ACT (Assertive Community Treatment). Onderzoek naar de rol van de therapeutische alliantie in de woonzorg setting ontbreekt grotendeels. In dit hoofdstuk wordt de sterkte van de therapeutische alliantie en haar relatie met het functioneren van cliënten en

(overeenstemming over) zorgbehoeften tussen cliënten (n=584) en persoonlijk begeleiders (n=105) onderzocht. Daarnaast wordt gekeken naar de invloed van zorgintensiteit (dat wil zeggen het verschil tussen BW- en BZW-begeleiding) op de relatie tussen therapeutische alliantie en begeleidingsuitkomsten voor cliënten. In zowel BW- als BZW-begeleiding is een sterkere de therapeutische alliantie geassocieerd met minder zorgbehoeften. In BW's was een toename in therapeutische alliantie ook geassocieerd met een hogere overeenstemming tussen cliënten en persoonlijk begeleiders over zorgbehoeften. Het is waarschijnlijk dat de begeleidingsfrequentie en -intensiteit van begeleidingscontact belangrijk zijn voor deze associatie. De hogere mate van afhankelijkheid van BW-cliënten op de zorg en ondersteuning van anderen zal leiden tot een grotere invloed van deze zorg op iemands dagelijks leven. Hierdoor ontstaat ook een grotere behoefte aan overeenstemming over de richting van de begeleiding. Onze bevindingen wijzen erop dat investeren in de therapeutische relatie tijdens BW-en BZW-begeleiding een middel is om zorgbehoeften van cliënten te verminderen. In het beschermd wonen draagt de kwaliteit van de begeleidingsrelatie ook bij aan de overeenstemming tussen cliënten en persoonlijk begeleiders over de zorgbehoeften waaraan moet worden gewerkt.

Hoofdstuk 7 Algemene discussie

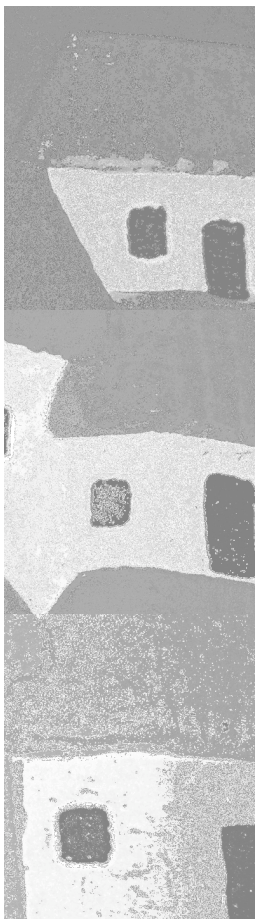
In dit hoofdstuk komen de sterke en zwakke punten van de UTOPIA studie aan de orde en worden de hoofdbevindingen van dit proefschrift besproken aan de hand van drie centrale thema's. Het eerste thema is '*deïnstitutionalisatie en haar gevolgen: een Europees perspectief op het verlenen van psychiatrische woonzorg in de samenleving*'. In hoofdstuk twee en drie wordt besproken dat cliënten van Europese woonzorg programma's erg op elkaar lijken, ondanks verschillende deïnstitutionaliseringsprocessen. Echter, de gemaakte vergelijkingen zijn beperkt door gebruik van verschillende terminologie, verschillende onderzoeksdesigns etc. Een recente Europese studie, (DEMoBinc), heeft een toolkit ontwikkeld om kwaliteit van zorg te vergelijken tussen landen en deze te relateren aan cliëntenuitkomsten zoals autonomie en kwaliteit van leven. Hoewel dit waardevolle informatie oplevert over de Europese institutionele zorg, bevat het geen aanknopingspunten voor begeleid zelfstandig wonen programma's. Daarbij ontbreekt er onderzoek naar en meetinstrumenten voor de dagelijkse zorg in BW- en BZW-programma's. Wij hebben tijdens de UTOPIA studie een eerste poging gedaan om een dergelijk meetinstrument te ontwikkelen (hoofdstuk vijf van dit proefschrift). Desalniettemin, deze methode is alleen toepasbaar op het geschreven product (het begeleidingsplan) en niet op de feitelijk uitgevoerde zorg. Deze daadwerkelijke RIBW-begeleiding zou op

vergelijkbare wijze moeten worden onderzocht. Daarnaast zijn vergelijkingen tussen landen nodig om het internationale inzicht te vergroten in de feitelijke zorgverlening aan cliënten in woonzorgprogramma's en tot op welke hoogte deze zorg rehabilitatie georiënteerd is. Dit soort gegevens ontbreekt momenteel volledig.
Het tweede centrale thema is 'zorgtoewijzing'. In hoofdstuk drie van dit proefschrift bespreken we de vergelijkbaarheid van BW- en BZW-cliënten met betrekking tot hun sociodemografische en klinische kenmerken. Dit maakt het waarschijnlijk dat een groot deel van de huidige BW-cliënten een overstap kunnen maken naar een zelfstandige woonsituatie. Dit is een belangrijk gegeven, zeker omdat RIBW's onder druk van de bezuinigingen hun residentiële populatie moeten gaan heroverwegen. Tot op heden heeft het onderzoek naar deïnstitutionalisering zich gericht op de overgang van het ziekenhuis naar de samenleving, in plaats van op een grootschalige verplaatsing van cliënten binnen die samenleving. Als dit laatste gaat plaatsvinden in Nederland, biedt dit de unieke mogelijkheid om dit proces te onderzoeken en inzicht te verwerven in de gevolgen van het vergroten van de autonomie van cliënten op hun herstel, empowerment en sociale inclusie. Deze informatie is niet alleen nuttig voor de toekomstige zorgtoewijzing van cliënten, maar ook voor de manier waarop woonzorg is georganiseerd. Daarnaast veranderd het financieringssysteem voor het begeleid zelfstandig wonen in de komende jaren. De gevolgen van dit beleid voor cliëntuitkomsten zouden nauwgezet moeten worden gemonitord.

Het derde en laatste thema is '*sociale inclusie*', wat wereldwijd verre van succesvol verloopt voor mensen met ernstige psychiatrische ziekten. RIBW's zetten zich in voor het vergroten van de maatschappelijke participatie van hun cliënten, en in vergelijking met hun Europese tegenhangers lijken ze daarin relatief succesvol. Meer dan de helft van de RIBW-cliënten heeft betaald, vrijwilligers of beschermd werk. Echter, de ondersteuning die zij krijgen lijkt hoofdzakelijk gericht op het bieden van 'iets te doen', dan op het toewerken naar regulier betaald werk. Een andere drempel voor sociale inclusie is het ontbreken van voldoende kwalificaties om in aanmerking te komen voor een betaalde baan. Dit is het geval voor ongeveer 40% van de BW- en 35% van de BZW-cliënten. Opleiding en onderwijs voor mensen met ernstige psychiatrische ziekten is ondervertegenwoordigd in onderzoek, GGZ-beleid en -praktijk. Het integreren van evidence-based interventies in RIBW-begeleiding, zoals Individuele Plaatsing en Steun (IPS) en Begeleid Leren (BL) zou mogelijk kunnen bijdragen aan het verhogen van het aantal mensen dat een baan heeft of een opleiding volgt. Daarnaast moeten we hierbij ook sociale, culturele en economische factoren meewegen. Van de 160.000 mensen met ernstige psychiatrische ziekten in Nederland leeft 83% op of onder de armoedegrens. Dit is op zichzelf al een barrière voor sociale

inclusie. Het weerhoudt de Nederlandse regering er echter niet van de verplichte eigen bijdrage voor tweedelijns geestelijke gezondheidszorg, waarmee ze een volgende financiële barrière opwerpen voor maatschappelijke integratie en bovendien voor noodzakelijke zorg.

Tenslotte worden de implicaties voor toekomstig onderzoek besproken. Vanuit een Europees perspectief is onderzoek nodig naar (de effecten van) herstelgerichte zorg, gebruik makend van methodes van dataverzameling en monitoring die over landsgrenzen heen kunnen worden toegepast. In Nederland dienen de woonvoorzieningen van RIBW's en de GGZ instellingen vergeleken te worden op vergelijkbaarheid van de focus en uitvoering van zorg en de kenmerken van hun cliëntenpopulaties. Ook moeten er effectstudies komen om vast te stellen of deze verschillende zorgtypes verschillende resultaten opleveren met betrekking tot cliëntuitkomsten. Verder is er onderzoek nodig naar de heroverweging van de residentiële cliëntenpopulatie van de RIBW en gevolgen van overheidsbeleid (bijv. het veranderen van de financieringsstructuur voor begeleid zelfstandig wonen) voor cliëntuitkomsten op de lange termijn.



Dankwoord

Aan het einde van dit proefschrift wil ik graag iedereen bedanken die het UTOPIA-project mogelijk heeft gemaakt. Natuurlijk de RIBW Alliantie als opdrachtgever. Zij hebben alle vrijheid gegeven dit onderzoek op te zetten en uit voeren binnen hun instellingen. Ik wil graag de leden van de begeleidingscommissie bedanken, allen vertegenwoordigers van de RIBW Alliantie: Jaap Fransman en Jan Jumelet van HVO Querido, Jan Willem van Zuthem van Kwintes, Hella van de Beek van RIBW KAM, Maurits Beenackers en Bert Beentjes van de SBWU en Rob Joosten van RIBW Gooi. Daarnaast bestond deze commissie uit twee externe experts, met ieder hun eigen invalshoek: voorzitter Jaap van Weeghel als hoofd van kenniscentrum Phrenos en Hannie Boumans namens Ypsilon. Bedankt voor jullie voortdurende belangstelling voor dit onderzoek en kritische blik. En Jaap, ik hoop dat we in de toekomst nog veel samen kunnen doen!

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Het UTOPIA-project is een erg vruchtbaar project gebleken. Toen mijn derde kind (en de zesde 'UTOPIA-baby') zich aandiende, vreesden jullie dat het drukke gezinsleven thuis de overhand zou krijgen. Gelukkig heeft dat nooit invloed gehad op het verloop van de begeleiding en heb ik het uiteindelijk kunnen waarmaken. Dat is ook te danken aan mijn tweede copromotor, Ellen, jij bent er één uit duizenden! Je bent niet alleen een fijne collega maar inmiddels ook een goede vriendin. Jij hebt de afgelopen jaren, of moet ik zeggen zwangerschappen, de continuïteit van het UTOPIA-project gewaarborgd. Hierdoor konden we onze strakke schema's halen. Ik heb ontzettend veel van jou geleerd, zowel op het gebied van data- en projectmanagement als op het gebied van data-analyse en het schrijven van artikelen. Daarnaast kon ik altijd bij je terecht met vragen, om te brainstormen, m'n gedachten te ordenen en te ventileren: bedankt!
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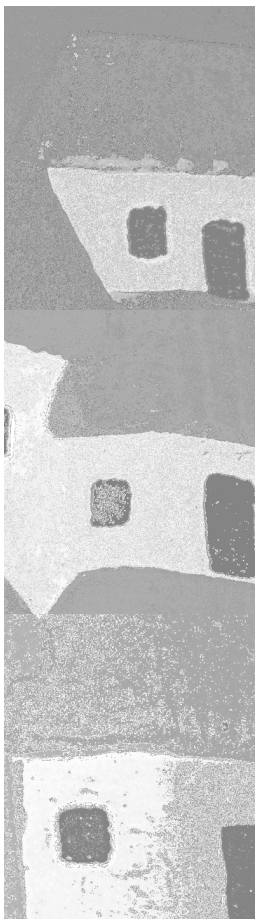
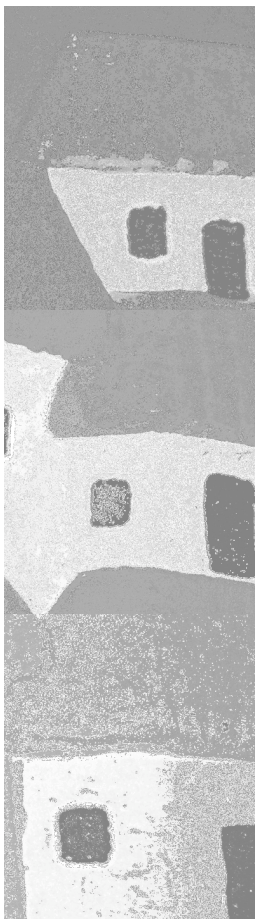


Curriculum Vitae

Charlotte de Heer-Wunderink is geboren op 24 oktober 1981 te Rotterdam. Na het behalen van haar gymnasium diploma in 1999 in Dordrecht ging ze Nederlands Recht studeren aan de Erasmus universiteit in Rotterdam. Ze behaalde haar propedeuse met judicium *met genoegen*, maar koos daarna voor een andere studie. In december 2003 studeerde ze af aan de Rijksuniversiteit Groningen aan de opleiding Neurolinguïstiek, in de afstudeerrichting experimentele taalkunde. Van 2004 tot 2006 volgde ze aan de Noordelijke Hogeschool Leeuwarden de duale opleiding HBO-verpleegkunde in de psychiatrie. Als leerling-verpleegkundige werkte ze anderhalf jaar bij de GGZ Friesland: eerst een half jaar op de afdeling ouderenpsychiatrie in het Jelgerhuis in Leeuwarden en een jaar als ambulante hulpverlener bij het Kernteam Langdurige Zorg in Drachten. Tijdens deze opleiding was ze ook een jaar actief als onderzoeksassistent bij de afdeling Onderwijs & Onderzoek van de GGZ Friesland. Gelijktijdig met het behalen van haar verpleegkundig diploma in april 2006, begon ze als promovendus op het UTOPIA-project bij het Rob Giel Onderzoek*centrum*. Daar is ze momenteel nog steeds werkzaam als onderzoeker. Sinds september 2011 is Charlotte eveneens als onderzoeker betrokken bij het Lectoraat Rehabilitatie van de Hanzehogeschool in Groningen. Daar houdt zij zich o.a. bezig met onderzoek naar Begeleid Leren interventies voor mensen met psychiatrische beperkingen en het integreren van (praktijkgericht) onderzoek in het onderwijs.



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